



Profound Intellectual and Multiple Disability Report for the North Lancashire Learning Disability Partnership Board

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Foreword by the Chair of the Profound Intellectual and Multiple Disabilities Sub Group

People with Profound Intellectual & Multiple disabilities (PIMD) are one of the most vulnerable groups of people within our society today. They, their families & carers face major obstacles each & every day of their lives just to enable them to participate in ordinary day to day activities which most of us take for granted.

Our inspiration for this project was our desire to discover what life was like locally for people with PIMD, their families & carers and in part the Mansell report 'Raising our Sights' (2010), the Mencap Lambeth Report (2010) and Mencap's 'Involve Me' project. What these reports show is that provided the right levels of support are offered that meet the aspirations of people with PIMD, their family & friends that these citizens will become & be seen as valued members of our local community.

The future holds many challenges with immense consequences for people with PIMD & their families. For example, the loss of the Independent Living Fund which may have a devastating impact upon individual's lifestyle & support needs. Changes to the benefits system, for example, the new Personal Independence Payments may greatly affect people's ability to get around their local & extended communities. While changes to housing benefit in the form of the room supplement, commonly known as the "bedroom tax" may lead to unsettling, unacceptable & unnecessary changes in the person's housing circumstances.

However, due to the continued development of personalised budgets (and of personal health budgets) which puts control firmly in the hands of the individual, their family & friends and the innovative impact that technology is having on the development of practice, particularly on communication & mobility the future, I believe, remains bright.

The conclusions and recommendations in this report are extensive and whilst cover the area of North Lancashire, they strongly reflect the state of health care and social care services and people with PIMD's experiences in many parts of Lancashire. Many insights we have gained are reflected by Mansell (2010) and the Lambeth Report (2010).

This report could not have been produced without the assistance of the local Learning Disability Partnership Board, the families, friends & carers

of people with PIMD & a small dedicated group of people who have worked hard to find a suitable vehicle to gather the information, analyse the data & produce this report. Their enthusiasm to see the task through to the final conclusion has been an inspiration to everyone associated with this project & to them I offer my sincere & grateful thanks.



David Grandy

Family carer and chair

Introduction by the PIMD Champion

I joined the PIMD sub-committee as a single parent carer, hoping to improve the life of my lovely 27 year son and others like him. My aspirations for my son are for him to have a full, active, socially inclusive life that makes him, happy, self-affirmed, fulfilled and always moving forward with his personal goals.

My problem as a carer is how to enable this to happen in a confused sea of professionals and situations that might unwittingly view my son and other people with PIMD as a series of boxes to be ticked, not as a complete individual with needs to belong in life.

So, when I was approached to be a champion for PIMD, with trepidation I agreed. It soon became obvious to us as a group that we needed to ask other individuals with PIMD and their families and support networks how it was for them.

What areas of concern did they have? What worked for them? Were there any inconsistencies that kept cropping up? Could we as a group address these issues to mobilize change? Did people with PIMD and their supporters have a voice in their area? Could we praise the good things and encourage and support them? Could we help people with PIMD and their carers to feel empowered and not alone?

I can vouch for the difficulty of daily tasks in life that enable someone with PIMD to get up and join in an activity, and the problems of health, obtaining suitable equipment, all these can cause endless complications.

People with PIMD are a small population, but are valued and precious nonetheless. This needs to be promoted in our community so they are not forgotten in the vastness of government and decision making, but valued individually for who they are, and how they can enrich and contribute to the broader community.

I hope this survey is the first step to support and enable change for individuals with PIMD that can be built upon in the future. The fruition of the survey will hopefully lead to a good foundation for growth and in changing the lives of individuals with PIMD for the better.

Lynette

Purpose of Report

People with a Profound Intellectual and Multiple Disability (PIMD) are often not represented in decision making. Valuing People Now: A Three Year Strategy (2009) advised that service providers, commissioners and policy makers were not specifically addressing the needs of these groups including those with complex needs. It was the intention of the Profound Intellectual and Multiple Disability Group to strive to find out what the issues are for this group of people locally and seek to bring these views to shape and influence services. The group wanted to engage with this minority group in a meaningful way and ensure their involvement in the work of the Partnership Board. (See Terms of Reference in the Appendices). They then wanted to work to see improvements and changes within the systems and organisations which influence the quality of life of someone with a PIMD.

It is hoped that the report will help shape and change service improvements across all sectors of the community to make sure that they are increasingly person centred and making reasonable adjustments to ensure good quality services, supports and facilities.

The report will be shared widely with the Partnership Board, the Council, health partners, councillors, providers and wider community stakeholders and groups as well as with the original participants via the Partnership Board website.

Since the information from the questionnaire has been gathered the PIMD Sub Group have been actively working and lobbying on issues raised within this report. Throughout the report we have recorded some of the actions the group have achieved to date.

The PIMD group hope you find this report informative, challenging and interesting.

The Questionnaire

The PIMD Sub Group formed a group to devise the questionnaire based on ideas from the Lambeth PMLD Project report and the Mansell Report. Working with a researcher and family carers the twelve sections were mainly devised with the simple format of 'What's great' and 'What could be better' similar to headings used in person centred planning. The sections on the questionnaire are: Health and Well-being, Support for Un-paid Carers, Respite and Short Breaks, Your Community, Employment and Day Activities, Education and Training, Transport, Housing, Benefits, Information and Advice, Specialised Equipment and Other. The final category existed so that people could give us any information which they could not place within another of the categories but felt important to share.

The questionnaire went through a design and development phase and was piloted by several family carers. It was decided that though the questionnaire was on the long side, we wanted to give families and paid support enough space to talk about what was most important to them.

The questionnaire was then sent out to 137 individuals who commissioners and colleagues identified as known to social services as having a PIMD. In total we sent out 195 questionnaires. If the individual who has a PIMD lived with their family carer they received one questionnaire. If the individual lived separately to their family carer they received a questionnaire and their family member also received a questionnaire. This was to give the opportunity to all family carers to respond, as we acknowledged that it is often the family carer who has the most knowledge about the individual.

Forty questionnaires were returned, which is a total response rate of 5%. A small number of these could not be used within the report, so the total number of questionnaires was 37 and the final data was made up of information about 35 individuals as two individuals had responses from both their family carer and paid support staff.

Definition of PIMD used for the questionnaire

With the questionnaire we sent a letter to all participants explaining what Profound Intellectual and Multiple Disabilities (PIMD) meant for the purposes of our questionnaire and to set the scene.

Some people use the term 'complex needs' or 'profound multiple learning disabilities'.

For the purposes of the questionnaire we took 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 the Mansell Report, 2010, p3)

Details of the Population of North Lancashire

When the report mentions North Lancashire this is the administrative districts of Lancaster, Fylde and Wyre, but does not include Blackpool. North Lancashire has a population of 321,881 according to the 2011 Census.

Total numbers of adults with learning disabilities in North Lancashire

The number of adults aged over 18 with a learning disability who were known to the Local Authority social care services as at 31st March 2012 was 1,470. 15 people are from a black or ethnic minority group.

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

At the time of the questionnaire 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).

Where people live

Of the 195 (137 individuals) questionnaires sent out 40 were returned. There were issues with 5 forms which meant that we were only able to include information about 35 individuals. This is the equivalent of 4% of our known population of people with PIMD.

Out of the 35 people about whom we have this information:

9 people live in the family home

26 people are not living in the family home of these:

4 people live in a residential care home

21 people live in supported living

1 person lives in the 'Shared Lives' scheme.

Shared Lives is when a paid carer who is not a family member is registered to have someone with a disability living with them in their own home and provides that person's support. This service used to be called Adult Placement.

Age

9 people are aged 18-25

24 people are aged 26-65

2 people are aged 65+

Gender

8 people are female

27 people are male

Black and Minority Ethnic Groups

2 people out of the 33 people about whom we have this information are from a minority ethnic group.

Older carers

None of the family carers supporting the person at home was over 65 years old.

Funding

Thirteen people had their care managed by the local authority with only five families managing the person's budget. Ten people take a Direct Payment and half of these people live with their family carers.

Seven people could not answer the question about how the person receives their social or health care funding. Only one person was using Continuing Health Care funding.

Continuing Health Care is free care outside of hospital that is arranged and funded by the NHS. It is only available for people who need ongoing healthcare and meet eligibility criteria. NHS continuing healthcare is sometimes called fully funded NHS care. If a person's needs are mostly health related the NHS is responsible for supporting them. This means a package of care is arranged and funded solely by the NHS.

Who answered the questionnaire?

19 family carers answered the questionnaire.

9 of these family carers live with the person they support.

10 were family carers of individuals with PIMD but were not living in the family home.

21 paid support staff completed the questionnaire. These were made up of managers, team leaders and support workers.

We received a very similar number of responses to the Lambeth PMLD Project questionnaire.



Health

The national picture

It is widely understood that all people with a learning disability, but particularly those with PIMD, have difficulty accessing good-quality healthcare. The Confidential Inquiry into Premature Deaths of people with learning disabilities in 2013 found that people with learning disabilities are likely to die 16 years earlier than the rest of the population. One of the main causes of death was respiratory problems.

People with PIMD have a number of complex health needs. They may have issues such as complex epilepsy or they may be technology dependent, needing oxygen or tube feeding for example. As a result it is especially important that they have access to both mainstream and specialist healthcare. These are needs that will grow as a greater number of children, with more complex health care requirements, move into adult services and because life expectancy is increasing. (p34 Lambeth PMLD Project).

In “Raising our Sights” (2010), Jim Mansell stated;

“People with profound intellectual and multiple disabilities have substantial, sustained, complicated health care needs. All the problems identified recently in the health care of people with learning disabilities apply to adults with profound intellectual and multiple disabilities. In addition, people with profound intellectual and multiple disabilities face several specific problems where services for adults are often not sufficiently well-developed to recognise and intervene effectively:

- (i) Postural care: failure to protect body shape, damaging movement, breathing and eating
- (ii) Dysphagia: problems swallowing, damaging nutrition, breathing and resistance to infection
- (iii) Epilepsy: poorly controlled seizures, preventing activity and engagement.”

It was recommended that “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,

dysphagia, epilepsy and investigation and resolution of pain and distress.” (Recommendation 11, Mansell, 2010). Advances over the last 30 years in the approach and education about postural care have improved the health and longevity of life for people with PIMD.

The local picture

From the questionnaire it was clear that not all adult health services were meeting people’s needs; there were comments that services were not providing a good service for people with PIMD and generally not providing a joined up approach:

“Health service staff tend to struggle when dealing with people with a profound learning disability.”

Paid support staff Lancaster

“It was only when he was 30 he was able to access (chest clinics) as the GP's never suggested or referred until we asked! [Generic] Physiotherapy never passed us on to chest clinic! (There are) long waiting lists for Physiotherapy and Occupational Therapy appointments and poor communication between the two.”

Paid support staff Fylde and Wyre

The example above is similar to the evidence produced in the 'Confidential Inquiry into premature deaths of people with learning disabilities' from 2013. This inquiry found that the most common reasons for deaths being premature amongst people with learning disabilities were delays or problems with diagnosis or treatment, problems identifying needs and problems providing appropriate care in response to changing needs. The stark findings were that 42% of deaths of the 238 reviewed in the inquiry were considered to be premature; that is if things had been different the person would have lived for at least one more year.

The median age of death for men with a learning disability was age 65 compared to the UK population which is age 78.

The median age of death for women with a learning disability was 63 compared to the rest of the UK population at age 83.

For more information please see **Confidential Inquiry into premature deaths of people with learning disabilities: www.bris.ac.uk/cipold/.**

It should be noted here that we observed a difference in the service provision between Fylde and Wyre and Lancaster as geographical locations. At the time the questionnaire went out, there were no specialist allied health professional services for people with learning disabilities or PIMD in Fylde and Wyre other than a very small speech and language therapy service. This contrasts significantly with the specialist speech and language therapy, clinical psychology, occupational therapy and physiotherapy services, all available in the Lancaster district. This disparity ensures that the healthcare of individuals needing these specialist services remains a postcode lottery and there continues to be an unequal service across North Lancashire.

Postural Care

Postural care is about using the right equipment and positioning techniques to help protect and restore body shape.

Postural Care: Protecting and restoring body shape' Mencap, p2

(See www.mencap.org.uk/posturalcare for written information and videos.)

Postural care is important to many people with PIMD because failure to protect body shape can have a considerable impact on a person's health and quality of life. It can even cause premature death. Sitting or lying in similar positions for large amounts of time may put the person's health at risk by developing pressure areas and distortion of their body shape.

Postural care needs were highlighted in the returned questionnaires with issues about wheelchairs being mentioned frequently. A high number of respondents, twenty-five out of thirty-five people use a wheelchair. Many people with PIMD and their families and supporters are therefore reliant on wheelchair services. This is an important issue to get right.

“The wheelchair constantly has problems, we got an assessment and a new chair but it was exactly same as the old one, with the same problems.”

Paid support staff

One respondent highlighted unmet need for one person who;

“...has a pronounced stoop which can affect her balance and mobility at times. This issue needs to be addressed further to ensure her mobility needs are maintained for general health and wellbeing. (She) needs an assessment.”

Paid support staff

The PIMD Sub Group looked at all the comments about wheelchairs from the questionnaire and held a themed meeting to look at these main issues. We wrote a letter to the health services dealing with wheelchair services and were invited to attend a meeting with the Quality Manager at the Specialist Mobility Rehabilitation Centre. We asked the managers a series of questions based on the questionnaire responses and experiences of group members. For example one person said:

"We can often have a long wait for repairs and the wheelchair is essential for day to day life."

Paid support staff

There was also an issue to do with servicing wheelchairs which is not always done immediately. One family carer said that their wheelchair was 'great' and they get a 'back up' service for the wheelchair similar to the support received when using Children's services.

The responses received prompted the group to address the funding of wheelchair services and to approach NHS England. The group are now linked into the national review of wheelchair services being undertaken as this report is written by NHS England.

Recommendations

- 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 needing to support a decision under the Mental Capacity Act.

- That the PIMD group remain in contact and engaged with NHS England regarding wheelchair services planning and reviews.
- To promote postural care guidelines within training for medical professionals, social care staff and other relevant individuals.

Dysphagia

In relation to Dysphagia (eating and drinking difficulties), respondents either stated that there were no issues in this area, or they were generally confident that the person's needs had been assessed, they had a good support plan and that staff were sufficiently trained in supporting their needs.

“She has guidelines followed by staff to ensure she receives correct fluid amounts and food types, prepared according to the above.” Paid staff

“We have had very helpful advice and assessment from the speech and language team to help with eating and drinking issues to reduce choking episodes.” Paid staff

Coordinating Healthcare

When coordinating the healthcare around a person with PIMD, it is good practice to involve all relevant health and social care professionals and care staff. One respondent highlighted the difficulty in getting the relevant people together in order to make a decision in the person's best interest (following a capacity assessment which deems the individual unable to make that particular decision for themselves):

“Best interest meetings are usually difficult to plan, ensuring all people are present.” Paid staff

It was also clear from several other responses that there are often differences of opinion between family, paid staff (if involved) and health services;

“We were continually locked into a battle with the provider; in the end our son did receive treatment as we requested.” Family carer

One respondent wrote that it would be better if "**the dentist and family could agree - both want the best but have different views**" Paid staff

It is interesting to note that generally people are not sure about using the Mental Capacity Act and Best Interests decision making would influence such considerations.

"...professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act 2005, in particular regarding assessments of capacity, the processes of making 'best interest' decisions and when an Independent Mental Capacity Advocate (IMCA) should be appointed."

Confidential Inquiry (2013) p6

If the individual themselves is proved to not have capacity about that specific issue, through the five part test, then a best interests decision can be made if there is contention. Generally, it would be the physician who states that in the best interests of the person the medical intervention should be carried out. An Independent Mental Capacity Advocate could be asked to get involved regarding health issues to assist with the understanding the person's mental capacity and best interests decisions, if no family or friends are available.

The term 'a person who lacks capacity' means a person who lacks capacity to make a particular decision or take a particular action for themselves at the time the decision or action needs to be taken.

Mental Capacity Act Code of Practice, (2007), p3

Chapter Four of the Code of Practice states that if a doctor or healthcare professional proposes treatment or an examination:

"they must assess the person's capacity to consent. In settings such as a hospital, this can involve the multi-disciplinary team (a team of people from different professional backgrounds who share responsibility for a patient). But ultimately, it is up to the professional responsible for the person's treatment to make sure that capacity has been assessed." (2007) p54

It is important to have all parties involved to gain a best interests decision or support someone in their life choices at a Person Centred Review or Social Care Review. Members of the PIMD group have commented upon the difficulty of getting all professionals and relevant parties together to achieve positive decisions and changes for the individual.

There is concern that professionals including medical professionals lack confidence to use the Mental Capacity Act and Best Interests decision making to support individuals in their life choices and important decisions.

Family carers may expect the staff support team to have professional knowledge about equipment, aids or necessary supplies, however, a family carer wrote about how they had to push for the use of a different type of continence aid; **“Neither the staff manager or his support team knew anything about continence aids apart from pads.”** When asked what could be better they wrote **“Staff training - awareness of products, some staff don't want to support him with this system.”**

A paid staff member expressed frustration at the confusing systems they deal with; **“When asking for an increase for his pads we were told that if he was reassessed he could be entitled to fewer!”**

Another strand in the questionnaire responses is that once the service is accessed (be it for dental treatment, incontinence or wheelchair services), there are often disagreements between those involved in getting the right treatment for the person, and that best interest meetings are difficult to co-ordinate.

Finally, there seem to be anomalies in services, demonstrating that some are not person centred which make it more difficult for those advocating on the individual's behalf to get things right for them. However, there are examples of good practice where individuals have received a robust, person-centred service which enables the individual to live a full, active and healthy life.

We need to be celebrating good practice and campaigning for better services for this group of people. Some examples of positive experiences are below:

“The dentist takes plenty of time and prescribes special toothpaste.” Paid support staff

“Agencies are aware of his needs and usually respond appropriately. The Learning Disability nurses are usually helpful and available.” Paid support staff

Summary

There are different strands that can be pulled out from the responses to the health questions. One strand seems to be getting access to the right treatment in the first instance, with many respondents mentioning waiting for assessments, or not knowing what was available, and not getting unless asking or fighting on the individual’s behalf. This reflects the report and recommendations from the Confidential Inquiry, 2013 which states that delay in getting a diagnosis and treatment was sometimes the cause of premature death.

Recommendations

- For each individual with PIMD to 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)

- For the government to establish 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.



Specialised Equipment

Specialised equipment includes hoists, wheelchairs, walking frames, beds, sleeping systems, boots and moulded seating amongst other things. It helps people to mobilise, get access to their community, feel comfortable and have a good life.

It was highlighted that people experience a very different service when the person they support is 18 years old and starts to receive adult services.

"In children's care you have direct access to occupational therapy and physio. Now as an adult we have nothing. There has been no reassessment of his needs even though there have been lots of changes in his size and medical condition. It has to be referred by the social worker then doctor just to speak to an OT." Family Carer, Fylde and Wyre

"Specialist equipment is often extremely expensive and funding is now cut or hard to get. Big problem!"
Family Carer, Fylde and Wyre

Finally, we asked people to list the specialised equipment that they used and provide comments about what is great and what could be better.

We asked: **What is great?**

"The wheelchair is great and this is the one piece of equipment where the back-up has remained the same as in Children's Care."
Family carer

"The seat is specially moulded to fit, it's easy to push and if repairs are needed they come here." Paid staff

"(The hoist) allows for easy transfers from bed to wheelchair and in the bath etc." Paid staff

"(The Rise and Fall Bed) is great for all staff to move and handle; it's more comfortable." Paid staff

"(Boots) were made to fit, free, easy to get appointment, choice of colour." Paid staff

We also asked: **What could be better?**

"We can often have a long wait for repairs and the wheelchair is essential for day to day life." Paid staff

"He is in my opinion is too big for his wheelchair. He needs to be re-assessed. We are waiting for an appointment." Family carer

Some people stated they would like a power pack for their manual chair. Others commented that the servicing of wheelchair was not always done immediately. People have concerns that they cannot get a suitable wheelchair using the NHS wheelchair voucher scheme citing little choice over the model and supplier. Another problem is that you have to pay to have the wheelchair to be maintained and fixed when choosing to buy a chair using the voucher scheme. One individual also thought that "chairs should really be adapted specifically for the individual." Implying that the chair the individual used had not been adapted and therefore was not sufficient for their needs. When representatives from the PIMD group visited the local wheelchair services they stated that their chairs are adapted for the individual according to an assessment. See appendix for full report of the visit.

The experiences locally mirror the national picture of services as reflected in the Mansell Report (2010):

"At present, wheelchairs are often a major source of difficulty for adults with PIMD. Individuals often have to wait months or years for wheelchairs; the chairs provided are often not suitable for the postural care or use of the individual; their repair is often difficult to arrange." p25

It appears that the struggle to get quality person centred wheelchair services is a national problem and not just a local one.

The feedback about specialised equipment also mentions other aids which can support the independence of someone who has profound disabilities.

"(Simple switches for the environment) are never used and are not connected." Family carer

Switches help individuals gain independent access to their environment. You can add a switch to virtually any electric item, for example a lamp, a television, a computer, a heater and a kettle or food mixer amongst other items. The individual then operates their own equipment via this switch which can be mounted somewhere nearby to be accessible by them at all times. They are then in control of their own environment.

The questionnaire highlighted there is a need for information about assistive technology. For example, one paid staff member had not heard of an epilepsy sensor but felt that this would be more suitable than using a baby monitor to monitor seizures.

Again, the local experience, gathered via the questionnaire demonstrates what the Mansell Report (2010) recorded in the section about communication aids & assistive technology:

"The great potential represented by research on the use of micro switches is beginning to be reflected in schools & further education. For adults, the obstacles to their wider use are that knowledge about the possibilities is scarce in adult services, that no one is responsible for their provision & maintenance, and that staff may not be aware of the importance of responding consistently to them to sustain the person's motivation to use them. As with wheelchairs, some people find that the equipment they use at school is not transferred to, or otherwise available from, adult services." p26

The PIMD group have regularly received feedback from family carers regarding the problems of school leavers not being able to keep their equipment if the school has paid for it. This means that the family have the expense and inconvenience of having to find the same equipment that their child is used to accessing to make their life more independent. Advice and support to the family does not always appear to happen at the child's transition to adult services on leaving school. If the family cannot, for example, find or afford the equipment, or are not supported to understand how to use the equipment or the importance of their child using the equipment, years of schooling and vital learning can be lost. Mansell recognised the need for a government led remedy to the problem of communication aids and funding:

"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."

Mansell (2010) Recommendation 18 (see Appendices for full list of recommendations)

Other issues relating to specialised equipment include comments about specialist boot fittings include family carers wanting reminders when the

person they support is due for more shoes. Others commented that boot fittings can take a long time and may involve lots of fittings.

Family carers would like **"access to specialist equipment at home so the individual can stay at home."**

People also said there is a **"limited choice of toilet aids for adults with hip problems, (and a) reluctance to find bespoke aids. There is a 5 year wait."** Others commented that new models of replacement equipment are not as suitable as previous models.

Summary

It appears from this section that many people were generally happy with the specialist equipment they were using but could think of areas for service improvement. One area where they feel the quality of back-up is the same as in children's services is wheelchair services, but it was felt clarification was needed regarding use of the voucher scheme and the service the Wheelchair department provide.

You can find a summary of our visit to the Specialist Mobility Rehabilitation Centre in Preston in the Appendices. The problems identified within the questionnaire were taken to the head of Specialist Mobility Rehabilitation Centre in Preston by letter and in person. The group are now in contact with NHS Wheelchair Summit and National Review and are able to add input to this work.

Recommendations

- 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 move the disabled person.

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.



Annual Health Checks

From 2008 the government has arranged that all adults with a learning disability on a social care register (including people with a profound intellectual and multiple disability) can access an **Annual Health Check** through their GP. This allows doctors to identify who on their lists has a learning disability and offer them an annual health check, often carried out by the practice nurse.

Annual health checks are seen as a 'reasonable adjustment' to help ensure that the health inequalities experienced by people with learning disabilities are eradicated. GP surgeries get paid for this work. Learning Disability nurses approached each surgery to offer training to the practitioners. However, GP surgeries were not obliged to sign up to this Direct Enhanced Service (DES) and some did not. In North Lancashire, all but one of the surgeries had signed up for the Direct Enhanced Service (DES) by 2012-2013.

The questionnaire shows that individuals are more likely to receive an annual health check if they are not living in the family home. Out of the 9 people living in the family home, 5 of these were accessing the annual health check, just over half.

This is in contrast to the people living in supported accommodation. 22 people accessed this out of 25 living in supported accommodation, this represents over 80% of respondents.

One family carer commented they did not know about the Annual Health Checks: **"We use the G.P when he is sick - nobody has informed us about this"**.

Generally, most people were happy with the experience of the health check. Out of 34 people 12 said the quality of their health check was good.

"It's ok but as he has a lot of ongoing medical appointments it just seems to be one of many and most medical things have to go through his consultants. But I do think in general it's a good idea."
Family carer

The Annual Health Check was a **“Good experience, (they) send us an appointment in plenty of time and (are) always person centred and professional”**. Paid staff

Some people reported difficulties with the health checks, citing problems with the amount of time given at the appointment and the quality of the check.

“The last time my client had (an Annual Health Check) his weight and epilepsy was checked but they did not check his blood pressure nor his heart rate or pulse.” Paid staff

One respondent showed that if a health check is not done well it is not valued or helpful:

“Didn’t really value the experience, very little information was asked about him and little or no advice given.” Paid staff

Summary

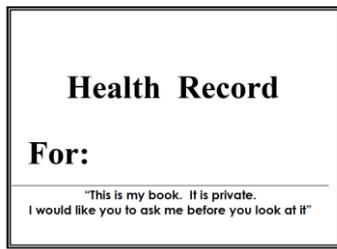
People who had experience of the Annual Health Check generally were pleased.

The majority of people living in supported living or residential accommodation are getting Annual Health Checks.

Individuals living with family carers are less likely to know about or have an Annual Health Check.

There are issues around the quality of the Annual Health Check including surgeries not making 'reasonable adjustments', for example not giving people longer appointments and not doing a full health check as recommended in the Cardiff model (Kerr, Jones, Hoghton, Houston, Perry, Thapar & Tomlinson, 2012). People also did not think enough advice was given at appointments.

Quality information is needed to provide a good health check and some respondents state that they were not asked for much information about the person supported leading to the conclusion that a thorough health check was not undertaken.



Health Action Plans

A Health Action Plan is a personal plan about what people need to do to stay healthy. It lists any help that people might need in order to stay healthy and makes it clear about what support is needed. It also contains historical health information which supports continuity of healthcare.

The questionnaire showed that people were more likely to have a health action plan if they were supported by paid staff. Some families, and even some paid staff were unsure what a Health Action Plan was.

We asked: **Does the person have a Health Action Plan?**

Family carers of person living at home:
3 out of 9 said yes, approximately 33%
2 said no
4 said don't know

Paid staff:
21 out of 26 said yes, 81%
3 said no
2 said don't know

We asked: **If the person has a Health Action Plan how has it helped or what could be better?**

Family carers of a person living at home answered:
"I think he has one. I think it lists all things I need to do/already do for him."

"Should he need to be cared for by someone else the relevant information is documented."

"It has helped to monitor and maintain his health as much as possible, also helped with research into new physiotherapy techniques."

"Helps focus the team on her health needs and keeps everybody involved 'in the loop' and up to date."

“When supporting her to the doctors, some doctors commented it was helpful to be there, other doctors did not want to look at it.”

“Passing on information to people who don’t know him”

“It enables everyone to be aware of health issues to support the individual’s well-being.”

“Improving his diet, cholesterol level (has) gone down.”

Summary

People who had experience of the Health Action Plan generally found it useful when communicating and dealing with health matters on behalf of the person.

The majority of people responding on the questionnaire living in supported living or residential accommodation have a Health Action Plan.

Individuals living with family carers are less likely to know about or have a Health Action Plan.

People have experienced health improvements as a direct result of having and using a Health Action Plan, helping the team around the person keep focussed, informed and current.



Hospital Passports

Research by mental health charity Mencap (2012) found that people with learning disabilities may find it harder to get equal care in hospital. The charity recommended the use of “passports” to support and enable people with a learning disability to show others, including healthcare professionals, who they are and what’s important to them. For people with PIMD the Confidential Inquiry (2013) recommended that:

"Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions." Recommendation 5 (p113)

The hospital passport is owned and controlled by the person themselves and information is entered under three categories:

- Red:** for vital facts staff need to know, such as personal details and medical conditions.
- Amber:** for things that are important to the patient, such as how they eat and drink.
- Green:** for likes and dislikes, such as television or noise.

From the questionnaire it appears that it is more likely that an individual will have a hospital passport if not living in the family home. Families are generally concerned that the person they support is not left alone in a hospital ward and appear to have strategies in place to ensure this happens.

We asked: **Does the person have a hospital passport?**

Family carers of person living at home:

2 out of 9 said yes (22%)

5 said no

2 said don't know

Paid staff:

15 out of 24 said yes (63%)

5 said no

4 said don't know

We asked if they replied "Yes" to please explain how it has helped or what could be better. The replies were:

“Helpful for hospital staff during stays (if they read it). We also have a hospital file we use - very handy as can give important information to ambulance staff quickly during an emergency - definitely beneficial.” Paid staff

“It enables the nursing team to get to know the individual whilst in hospital especially when they can't communicate themselves.”

Paid staff

“Just gave few tips on behaviour/habits really helped the nursing staff.” Paid staff

We also asked: **If you don't use the above documents, what do you do to help medical staff provide good support?**

“I have a folder with everything people need to know, although he is never left on his own anyway, I am always with him.” Family carer

“Things that concern us regarding if the individual needed to go into hospital are - he would need a parent or carer with him 24/7. Our experience of hospitals and their staff are: they have not the faintest idea what the individual’s needs are or what to do with him. This is true of even the people with a caring nature who want to help - never mind the others who just seem to fill in paperwork and hang round the nurse’s station on the ward. Hospital passports are all well and good - but the individual needs someone who knows him well to be with him at all times”. Family carer

“We try and do the care ourselves in and out of hospital”.
Family carer

“A client is accompanied by a member of staff that knows that client well and staff are sent every day to the hospital until the client returns.” Paid staff

“We just explain about his needs” Paid staff

Summary

More people supported by paid staff have a Hospital Passport and have reported finding them useful.

Family carers tend to have the information available in a similar format to a hospital passport, for example, in a folder or they pass the information on verbally.

Most respondents feel it is essential to be with the person most if not all of the time during their hospital stay to support the individual and to inform health staff of their needs.

When hospital staff use the passport well this ensures that the person's needs are met.

It is considered good practice for patient held records to be used in hospital, general practice and all health care settings. The Health Action Plan or the Hospital Passport are excellent documents alongside the essential Communication Passport. The PIMD Group and Partnership

Board are aware from listening to a number of personal stories that these are not always used or welcomed by medical staff.

In 2014 the Direct Enhanced Service introduced the Annual Health Check for anyone with a learning disability over age 14 and made it a stipulation that a Health Action Plan was completed for patients at their Annual Health Check by the GP surgery.

The Confidential Inquiry (2013) makes it clear via its recommendations (5 and 6, p108) that everyone with complex health care needs should be using these documents to help them gain equal access to healthcare.

At a time when the Confidential Inquiry (2013) found that people with a learning disability on average live sixteen years less than the rest of the population and '22% of people with learning disabilities were under 50 when they died', compared with 9% of people without learning disabilities (p2); when a court of law in 2015 found the NHS 'contributed to by neglect' the death of Connor Sparrowhawk at only aged 18 and when the Mazars Report (2015) has uncovered that only 4% of unexpected deaths of people with learning disabilities (4 out of 93) were investigated by an NHS Foundation Trust; it is more essential than ever that the National Health Service significantly improves its services for people with learning disabilities including people with PIMD. In 2015 a Learning disability mortality review has been commissioned by Health Quality Improvement Partnership on behalf of NHS England to ensure improvement in the quality of health and social care service delivery for people with learning disabilities. It will do this by looking at why people with learning disabilities typically die much earlier than average.

Health Recommendations

- Health care staff to be trained in person centred approaches and communication with people with PIMD
- The individual, family carers and supporters would benefit from having a lead care co-ordinator for people with more complex health needs to coordinate their assessment, healthcare and treatment and liaise between healthcare departments and professionals, taking a lead to follow up care coordination and provide this role if an individual needs hospital treatment.
- 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

- The local NHS Health Trust should address the inequalities relating to access to specialist allied health professionals across the whole of North 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
- The Partnership Board and health carer 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
- That 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.
- To encourage and support family members to complete Hospital Passports and Health Action Plans for their family member
- To educate all health staff to understand the importance of reading and using the Hospital Passport and Health Action Plan, particularly for individuals with PIMD where communication is different.
- That nurses and GPs provide people with more advice at their Annual Health Check
- Information is sent out to family carers to inform them about the Annual Health Check and what it is there for
- People carrying out health checks need to be aware of what 'reasonable adjustments' they may need to make to ensure each individual gets the most out of their health check

As a result of this research the PIMD group have established a team of family carers and academics who train medical students, doctors and nurses on a regular basis at two universities in the local area. The training has been devised by the group with the assistance of the speech and language therapist and local provider colleagues. The family carers input their personal experience. The training includes sections on having a fulfilled life, communication and posture and includes video footage. The PIMD group have inspired

and educated a new generation of doctors, nurses, health workers and learning disability nurses. Their next project is to train social workers in Lancashire.



Communication

Given that the definition for PIMD includes that the people 'have great difficulty communicating' (Mansell, 2010, p3) we hoped that we would discover some good practice through the questionnaire. Communication is essential for choice and control and living a good life in the way you want. Good communication could make reference to non-instructed advocacy or using a citizen advocate as well as equipment, technology and techniques like intensive interaction.

Communication with people with PIMD often relies on non-verbal communication, understanding people's body language, physical touch and interpreting vocal communication. Knowing a person over time helps to build up understanding about how they are feeling and daily choices, for example, what they would like to do. Family are essential to understanding this communication especially in relation to important topics like health or big life changes and in making best interests decisions or when a circle of support work together on a person centred plan. Many people also use a variety of communication aids. These can be basic or highly technical, from a simple switch to an iPad or eye controlled technology like 'eyegaze'.

A Circle of Support is a group of individuals and family members who know a person really well and are invested in devising goals and taking action to achieve the goals within that individual's life plan or Person Centred Plan.

The Mansell Report (2010) in the section about communication aids & assistive technology provides a national picture about the importance and issues relating to these essential pieces of equipment:

"The great potential represented by research on the use of micro switches is beginning to be reflected in schools & further education. For adults, the obstacles to their wider use are that knowledge about the possibilities is scarce in adult services, that no one is responsible for their provision & maintenance, & that staff may not be aware of the importance of responding consistently to them to sustain the person's motivation to use them. As with

wheelchairs, some people find that the equipment they use at school is not transferred to, or otherwise available from, adult services." p26 (See also recommendation 18)

In the questionnaire we asked: **What's great about communication?**

Many responded by highlighting how a Communication Passport had helped, and others have spoken about accessing support from the Speech and Language Therapy Service and using picture software at a local library. 2 respondents highlighted the use of technology as being helpful to communicating with the individual; "He has a communication passport on his own laptop" and a "Good talking (photo) album".

In their report 'Communication and people with the most complex needs: what works and why this is essential', Goldbart and Caton (2010) stated that "it is likely that in the future, communication passports could include video and audio files, giving a rich and detailed view of the person in different settings," so it is encouraging to see that people are starting to use technology for the benefit of sharing information about the person's communication.

There was, however, no mention of use of assistive technology such as micro switches to assist with choice making and expressing wants and needs. Jim Mansell (2010) draws from the research the importance of using of micro switches for people with PIMD. He recommends consistent use of switches for communication purposes to ensure that the person makes the connection between cause and effect.

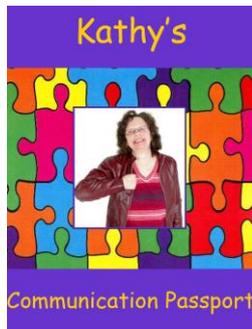
We asked: **What could be better about communication?**

Some commented that more training is needed in communicating with people with PIMD and in developing Communication Passports.

"Staff (not) understanding his communication. He is given very few choices in his life." Family carer

One paid staff reported that the person would benefit from a Communication Passport because understanding the person's way of communicating is very important to their wellbeing and that not all staff members are aware of the person's complex communication needs.

This example highlights the potential difficulties inherent in the person's highly individualised and often extremely subtle communication methods being understood by some, but not all of the staff team. The section below reports on whether communication passports are in place and their perceived value.



Communication Passports

Communication passports explain how someone communicates, for example, how they show they are happy, they don't like something or they are in pain. These are crucial documents to help form decisions around whether the person can consent to a particular decision, and to help develop a person centred plan.

21 of the 35 respondents told us they have a Communication Passport (58%).

We asked: **Does the person you support / your family member have a Communication Passport?**

Family carers of person living at home:

3 out of 9 said yes (33%)

5 said no

1 said don't know

Paid staff:

18 out of 26 said yes (69%)

5 said no

3 said don't know

Overall, 60% of respondents say the person they support has a communication passport.

We asked if people did use a communication passport to explain **how it has helped or what could be better?**

These are the answers we received:

“The communication passport has been useful at college with the tutors not knowing the client – it stops (the person) being anxious over being understood.” Paid staff

“This contains information on all aspects of his communication, helps new staff to understand his communication, which helps him.” Paid staff

“The information is very basic. I don't know of any occasion when this has been used or looked at. (It is) not updated on a regular basis.” Paid staff

“We are unable to put it on to our (computer) system because of confidentiality and security rules.” Paid staff

“Yes when we do have new carers it is very helpful but we also show how specifically to communicate with the individual and they pass this on to people at College, Health care professionals etc. We also have detailed plans and routines, written down for everyone to check that they are doing things right, but also because the individual's carers are like part of our family we use word of mouth and communicate all the time with the individual. We also show people what to do. They always ask if they are not sure. We have a great deal of trust between us.” Family carer

These responses demonstrate the value of Communication Passports and how they affect the person's everyday life, being understood and known as a person, being able to participate in community life and have good relationships. It also shows that despite having a Communication Passport, unless it is used and updated regularly, it is of no use to the person. This could have a major impact on their health and wellbeing affecting their inclusion in decision making and everyday life. It is possible that without taking time to understand the person's communication needs and capacity that behaviour that challenges could develop.

Services need, therefore to be particularly mindful of using all the resources available to them to support the individual. From speech and language therapy, occupational and physio therapy to Communication Passports, assistive and digital technology and other resources nationally available. In Lancashire we produced a 'Communication Checklist' which enables supporters, family carers and providers to check which communication aids would assist the person they support. There needs to be a culture of using these aids and Communication Passports regularly, keeping them up to date and person centred and in

a convenient place so that they can be used at any point to aid communication with the individual.

We asked: **If the person doesn't use a communication passport, please tell us how they communicate with others:**

“By the way he responds to people, stroking and smiling. He recognises people and understands what is spoken to him.”

Paid staff

“(It is) not very effective. People don't communicate with him - they speak to his support”. Paid staff

"I always give people a sheet with as much information as possible about what we think he means when he does things, even with this it is a process of elimination!" Family carer

“He does not speak. We have 23 years of experience of living with him, we know his needs.” Family carer

Each person's communication is unique and the people commenting above show a range of issues in trying to get a consistent approach to communication with the people they support. For some it is hard and based a lot of the time on guess work. Knowing the person with PIMD well and over a period of time aids this understanding which demonstrates how having a consistent staff team is essential to support someone with PIMD well to have everyday choices. The PIMD Group visited the Mencap 'Involve Me' project at Ellesmere Port in 2011. Members saw first-hand the value of and need for taking time to get to know the person and understand them to be able to work in a meaningful person centred way, taking into account their preferences and needs. The *Involve Me Summary Booklet* (2011) contains eight key messages about how to genuinely involve people with PIMD.

Understanding the subtleties of non-verbal communication, having the right values to support the individual by taking time to use a communication aid or piece of assistive technology helps the person participate in their world and be included in everyday life.

Summary

People who don't live in the family home are twice as likely to have a Communication Passport. This is perhaps because Communication Passport training has been offered to provider services. Families may not have received this information. It is important that families are informed about Communication Passports and encouraged to develop them so that all the information they have about their child's communication is available for others. The questionnaire demonstrates that where a Communication Passport is in place they are useful in supporting communication, reducing anxiety and promoting good relationships.

Since undertaking the questionnaire the Workforce Development Sub Group of the Partnership Board has put training for family carers on the agenda and has been looking into ways of providing family carers with training sessions. They have offered a series of workshops to family carers on positive behavioural support and person centred planning and managing conflict among other topics. Family carers were also invited to a Lancashire information day about assistive technology.

Recommendations

- Training in communication methods and in developing communication passports need to be regularly available to all paid staff and families
- More information about utilising assistive technology such as switches to help more people with PIMD develop and maintain communicative intention
- 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 including communication aids if bought for the individual and not the school
- 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.

A number of switches are available and can be sourced from catalogues like 'Inclusive Technology' or 'Spacecraft' as well as other suppliers

which can be found on-line. There may be other local arrangements for example, some switches can be loaned from the Morecambe District Disability Day Services by any person with a learning disability or their support. This enables people to try technology before purchasing equipment.

Since this questionnaire was completed a Communication Checklist has been introduced throughout Lancashire to support providers to think about the many different ways of communicating, the tools and technology people may find helpful. See Appendices. Many providers in North Lancashire have completed this checklist and supplied us with the information. This will help us improve our training to providers and others when thinking about communication.

The PIMD group have also designed a Communication Passport leaflet to share with stakeholders including family carers and providers. See Appendix 11.



Carers

'A carer is someone who provides unpaid, often intensive, support to family or friends who could not manage without that support. This could be caring for a relative, partner, friend or neighbour who is ill, frail, disabled or has mental health or substance misuse problems.'

The Multi-Agency Carers Strategy for Lancashire 2009-2012

One of our carers commented on their life as a carer:

"Life is difficult at times as it is hard to juggle working, being kept awake for most of the night and as soon as we get home from work start doing all the washing, drying, ironing and all his care before another sleepless night. It's hard not being able to just nip to the shops or just put your coat on to go for a walk. If things ran the same as in children's (services) and we didn't struggle getting equipment mended etc, it would make a difference." Family carer, Fylde and Wyre

The national picture

In 2009 one in ten of the population were caring for someone. (Multi-Agency Carers Strategy for Lancashire 2009-2012). In 2001 Carers UK published a report stating that 3 in 5 people will be carers at some point in their lives.

"The 2011 Census figures for the UK show an 11% rise in the number of carers since the last Census in 2001 - increasing by over 620,000 to 6.5 million in just 10 years." *Carers Uk Policy Briefing* May 2011

Caring involves difficult decisions and complex arrangements to make time to get a break, balance a job, get training or look after your health. The role carers undertake can often lead to isolation, poverty, ill health and loneliness. 'Carers at the heart of 21st century families and communities' (2008) and its refresh in November 2010 'Recognised, Valued and Supported - next steps for the carers strategy' outlines the Government's intention to respond to the needs of growing numbers of people who care and recognise that many people become carers at some point in their lives, acknowledging that the role can be both rewarding and frustrating.

Carers UK also published *State of Caring* in 2015 capturing the views and experiences of 4,500 carers in the UK and summarising four key priorities to recommend to the government: practical support, health and wellbeing, caring and work and financial hardship.

Carer's Allowance is a benefit available to people over 16 who support a person with substantial care needs for at least 35 hours a week. They don't have to be related to, or live with, the person they care for. It has been acknowledged by government departments that this benefit has consistently not been taken up by carers (See DWP 2010 report 'The take-up of Carer's Allowance' and Appendix for more details about Carer's Allowance and eligibility.) Carer's have made comments about this benefit in this report.

The Care Act 2014 also mentions the need for improvement in the support and assessment of carer's needs, recognising carers as partners, extending the right to an assessment to more carers, and introducing a clear entitlement to support to help them maintain their own health and wellbeing.

The local Picture

In Lancashire the Multi-Agency Carers Strategy was written in 2009, updated in 2013 and is being re-written in 2016. This states the local authority and health service intentions with regards to support for carers in Lancashire. Local citizens had the opportunity to influence the Strategy and it takes into account the national agenda mentioned above and local need. A variety of support is available to unpaid family carers including initiatives 'Time for Me', 'Peace of Mind for Carers' drop in services, forums and newsletters.

Advocacy services are available across Lancashire via Advocacy Access a single point of access for services. (See Resources for further information.)

At the time of this research family carers of adults and young people with learning disabilities including PIMD could attend the North Lancashire Learning Disability Partnership Board Family Carer Network with monthly meetings across Lancaster and Fylde and Wyre. Information and networking events occurred annually and there was a bi-monthly newsletter. The newsletter contained national, regional and local information with updates on major changes affecting people with learning

disabilities including benefits, consultations and new government initiatives or bills.

The Lancashire Partnership Board now keeps the family carers up to date via email and events through the Lancashire Family Carer Network.

Questionnaire responses about Family Carers

19 out of 36 questionnaires were completed by family carers.

Out of these 19 responses, 9 people with PIMD are living in their family home supported by unpaid family carers.

7 families are supporting a young person (18-25) and two families are supporting an adult aged 25-65.

5 families are receiving a Direct Payment.

4 families manage their own care package.

7 family carers completing the questionnaire were female, 2 were male.

7 are parents, 1 is a grandparent and 1 is a sibling.

All 9 family carers were in the 25-65 age group.

Responses from carers about what could be better for people with PIMD related mainly to services and social care being more person centred.

Person centred approaches are ways of working which involve and empower people in deciding what they want to happen in their lives. For example, doing a person centred plan, a one page profile, matching staff or a person centred risk profile. Please see the Person Centred Approaches and Planning information on the Ormerod website for more information and tools that can be used: <http://ormerodtrust.org.uk/pcp-tools/> or on Helen Sanderson Associates website: <http://www.helensandersonassociates.co.uk/person-centred-practice/>

"There still isn't a person centred culture in Social Services. He fits in with the service and his support. He has few choices in his life."
Family carer

"Restructuring at Social Services is not great, no contact with Social Worker or feedback since last year. New system is isolating."

Family carer

"Social Care and social work! More person centred and kind."

Family carer

One family carer commented that often social workers or reviewing officers from social care teams assessing people with PIMD have little or no specialist knowledge and are often unaware of the obstacles people their families and carers face in their day to day lives.

Support for Unpaid carers

Under several Acts of Parliament (Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004) people of any age providing a substantial amount of unpaid care on a regular basis to ill, elderly or disabled persons who are seeking help from adult social care services have a right to a separate assessment. This legislation, current at the time of the research, was replaced in 2014 by the Care Act. Carer's organisations recognise that the act 'simplifies, consolidates and improves existing legislation' for carers. (Carer's Trust, (2014)

The questionnaire asked about the support available from statutory services and support groups for unpaid carers. It asked what is great and what could be better about support for carers.

5 out of the 9 family carers giving direct support said they have had a Carer's Assessment. Only 5 family carers out of the 19 respondents have had a Carer's Assessment.

3 family carers said not they had not had a Carer's Assessment and the other 11 families did not reply to the question.

It appears that many family carers are unaware of the benefits and details of a Carer's Assessment and information needs to be more widely available to support their choice.

One of these carers commented: "they do a carer's assessment and I have a copy of it. I know groups and organizations...within the area but at present I don't feel the need to use them. I would for advice etc. if I

needed to and it is nice that they are there. I have support from family and friends."

Another carer commented that she does not **"feel confident that help would be available should it become necessary in a hurry. Although we don't have great health (especially my husband) no one offers any help or support unless you ask for it and then you feel guilty for asking."**

One carer felt she had a solution to the difficulty of not being able to claim Carer's Allowance when you reach pension age:

"When you reach pension age and are receiving a basic pension you are not able to have Carer's Allowance as well, but if you are not eligible for a full basic pension - why cannot the difference be made up with Carer's Allowance, just a thought."

From the comments received we are hearing that family carers often feel a burden and therefore won't ask for help. They also are not confident help will be available when they need it, for example, if there is a family crisis or a change of circumstances. On top of this their general well-being and ability to care for themselves may be affected because they don't accept social invitations as they know that the respite facilities probably won't be able to help them at short notice.

It is interesting to note that most family carers did not make any comments about Lancashire Carers and the services provided by Lancashire County Council. This raises the question of whether some of the most isolated and vulnerable families are aware of the support they can receive via these services.

The PIMD group has become aware of 'hard to reach' family carers who have never received services and are now older adults themselves still doing their full time caring role with no external support. The concerns are that family carers are coping without any formal advice or support because they are unknown to services. The individual with PIMD is likely to need services at a point of crisis with potentially no information about themselves and their unique support needs.



Respite and Short Breaks

People living with family carers are often entitled to short breaks or respite provision following an assessment of need. Respite provision can be accessed in a variety of ways, including nights in short breaks houses, Shared Lives, residential care or by using domiciliary hours. Carers are entitled to a carer's assessment and may also receive a small personal budget to enable them to get the support they need to continue caring.

In North Lancashire there are two Lancashire County Council run short breaks houses with 6 bedrooms in each. There are other short breaks facilities across the county. People can also use the 'Shared Lives' scheme which entails staying in a family home supported by registered paid supporters. Both schemes are monitored by the Care Quality Commission (CQC) the health and social care regulatory body. Individuals can access these schemes across Lancashire. Other options include using a personal assistant to move into the family home to support the individual while the family carers take a break away from the home. People may also like to use a residential home.

The questionnaire discovered that 5 out of 9 family carers supporting people with PIMD at home were receiving respite.

Out of those 5, the most frequently used respite was the short break centres. One person also classed the day service as respite.

4 families who provide support for their family member who has PIMD do not have respite at all. Two of these are because they do not consider the facilities or the service to be suitable for their family member.

We asked: **What is great about short breaks and respite?**

One family praised the short break and respite services because:

"The staff have worked with us and the community nurse to set up for his health needs. They follow what we've said to provide as near as possible the same care he has got at home."

Some individuals use personal assistants to provide their respite, the person can then stay at home supported by people they know. One family said: **"Our respite is extremely important to us especially as we get older. Also for her to be with other people and to be more independent."**

Other families have a lot of confidence in the respite they receive: **"I have a much needed break, he enjoys going and I am happy to leave him and trust the people who look after him."**

We asked: **What could be better about short breaks and respite?**

Issues family carers mention involve the difficulty of needing to book so far in advance and having to say no to spontaneous invitations.

Transferring the individual's equipment on every visit home is difficult.

The cost when you are on a very low income.

Using personal assistants to provide respite in the person's own home can be difficult if the paid staff are sick.

There also seems to be a concern about cut backs to care packages including short breaks and respite. A family said:

"Any cut backs in care would have an extreme adverse effect on both ourselves and the person we support. Services need to stay the same and intact. As we get older we will need more respite to be able to continue looking after her and for her to stay where she is happier."

Since this research was completed the government has withdrawn significant funding from local authorities meaning that social care cuts are inevitable. This is of deep concern to families and carers of people with PIMD due to the reasons outlined above. There is a huge concern for the quality of life and support the person will receive enabling them to have a full life in their community.

Summary

With regards to the comments above Mansell (2010) also stated that good services are:

- Individualised & person centred
- Treat the family as the expert
- Focus on quality of staff relationships with the disabled person
- Sustain the package of care
- Are cost effective

(Mansell, pp 8, 9, 10, 11, 12, 13, 14)

Mansell's discoveries reflect the findings of the PIMD group and summarise many of its conclusions.

Family carers have anxiety about retaining respite and if they will be able to get more when their need increases. Carers feel guilty about using services which may mean they are less likely to ask for the help they need when they need it potentially jeopardising their health. Families also see respite as an important opportunity for their family member to meet others, socialise and gain some independence.

When services are person centred, family members are really pleased with them. The opposite is also true and families have ceased to use services when the service has not been suitable or able to provide the unique requirements requested by family carers. This may involve their support plan or equipment. The PIMD group has also observed the comments regarding the differences between children's and adult's services. For some people replying to the questionnaire, adult services seem less joined up, causing difficulties for families. The amount of respite can also vary dramatically from children's to adult's services which affects families with young people coming up to transition at age 18 when they may be entitled to less respite.

There is also an issue regarding getting a short break when you need it, with people reporting little availability for breaks at short notice.

It was clear from the questionnaires returned that family carers not living with their relative who have PIMD are not aware about key crucial health initiatives, for example annual health checks, health action plans, hospital passports or communication passports. Carers are also not aware of or are not taking up the offer of a carer's assessment.

The Winterbourne Review (2012) highlighted the need to keep people local and connected with their families and communities in order to keep people safer. One family commented that none of the information requested in the questionnaire is known to the family because the family member had been in full time care for 25 years. Overall, family members completing the questionnaire where the individual is not living with them in the family home could not complete all the questions and often had very little information about their relative.

Carers are resilient and resourceful, they have good solutions to problems and can provide good information to support the planning and buying of services. Carers need to be kept informed, seen as 'experts by experience' and part of the 'care team' and included in important decisions about the person's life. They need to be listened to and taken seriously, especially when requesting more support or offering a solution to their family's problem. This is also echoed by Mansell (2010) where he states that good services treat the family as expert. It can be seen, more recently, where family views and knowledge about the individual were over looked that serious harm has befallen individuals in the care of the National Health Service.

One of the key messages from the recent independent review following the investigation, campaign and legal battle for justice for Connor Sparrowhawk whose tragic death aged 18 in an NHS foundation trust unit was 'contributed to by neglect', (The Guardian, 16 October 2015) demonstrates that families were not treated as experts by experience by the service and were not listened to or valued (Veritas, 2015, p20).

One observation the PIMD Group have noted is that often where there were examples of good practice families had taken a leading role, battling public services to get what they needed for their family member. They had recruited other people to help them – friends, other families supporting adults with PIMD, professionals from service providing agencies or commissioners of services and advisers from voluntary organisations. These were not always constructed as 'circles of support' but were clearly important sources of ideas, energy & commitment.

Since undertaking the questionnaire the Workforce Development Sub Group of the North Lancashire Partnership Board has put training for family carers on the agenda and has been looking into ways of providing family carers with training sessions. They have offered a series of workshops to family carers on positive behavioural support and person centred planning and managing conflict among other topics. Family carers were also invited to a Lancashire information day about assistive technology.

Recommendations

- Paid support workers need to communicate to family carers more around key essential information, for example, regarding health, meaningful daily activities, person-centred planning and finances.
- Services and social care teams need to be 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 need to be kept informed, seen as 'experts by experience' and 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.
- 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. This could be achieved via adult social care and providers hosting an annual assistive technology event.

These recommendations fit with the local authorities commissioning intentions for carers, the Care Act 2014 and the Mental Capacity Act 2005.



Your Community

In this section we looked at where people go and what they do with their time. We asked what their community services are like. People also commented on accessing community facilities.

The national picture

Within the Mansell Report (2010) 'Recommendation 25' states that '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.' (p29)

Mansell (2010) states that many adults with PIMD 'like to take part in everyday activities in the community and there is evidence of the imaginative use of personal assistants and individual budgets to enable this'. (p28).

Since December 1994 it has been unlawful for any provider of universal services to treat disabled people less favourably for a reason related to their disability. The Disability Discrimination Act in 1995 obliged service providers to consider 'reasonable adjustments' which are changes made to provide access to goods, facilities, services and premises. This includes for example, providing extra help or making changes to the way they provide their services.

The Disability Discrimination Act was replaced by the Equality Act in 2010 which brought together several acts to provide a single act to simplify anti-discrimination legislation which included the Disability Discrimination Act. The Act requires equal treatment in access to employment as well as private and public services, irrespective of the protected characteristics of age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex, and sexual orientation.

In 2014 there were rulings relating to wheelchair access on the buses. The first put a requirement on bus companies to make sure that wheelchair users can access the wheelchair space on the buses. The second ruling in 2014, however, overturned the initial ruling leaving people who use wheelchairs at the mercy of individual bus company policy or individual driver's support, with no legal requirement for either to make enforcements. In the nationally documented case 'Firstgroup Plc v Paulley' the appellant was granted an appeal to the Supreme Court which is due to be held during 2016.



Regarding access to the community and friends and relationships, the 'Stay Up Late' campaign has been supporting people's access to their community events and venues by raising awareness that many people dependent upon paid staff are struggling to stay out after 9pm. They also host discos and music nights including a Gig Buddy scheme. See their website for further details: <http://stayuplate.org/> Rotas and staff change-overs are cited as one of the main reasons people don't stay out late.



Luv2MeetU is an agency which hosts friends and relationships events like Speed Dating and Discos as well as being a dating agency. <http://www.luv2meetu.com/> Luv2MeetU also hosts other social opportunities, see their website for details: <http://www.hft.org.uk/supporting-people/empowering-individuals/friendship--dating/>

The local picture

In North Lancashire we have a very active Fulfilling Lives Group linked to the Learning Disability Partnership Board which included the Friends and Relationships Champions. The Champions produce a bi-monthly newsletter in an easier to read format with local events and activities to do each month including some specifically for people with learning disabilities and some for everyone.

The Champions in Lancaster also host a Cinema Club and a Really Enjoyable Dining Society alongside setting up some activities with partner organisations like Five Aside Football, Multi-sports, Gym Club, Pool Club and a Reading Group where people can be read aloud to. The group are looking into starting reading groups in the libraries using sensory stories and 'bag books'.



In Fylde and Wyre the U-Night group actively organise discos, quiz nights, fashion shows and other events including dining out and cinema trips. The U-Night group is headed up by a self-advocate with a passion to see people meet and make friends to avoid loneliness and stay in good mental health.

STAYING UP LATE QUESTIONNAIRE



What We Found Out

In 2012 React in conjunction with the Partnership Board did a survey in Lancashire asking self-advocates who have a learning disability if they are able to stay up late

and what are the reasons they can't or don't. The report can be found on the North Lancashire Partnership Board website:

<http://www.northlancs.cswebsites.org/default.aspx?page=23648>



In the North West Wigan support 'You'll Never Watch Alone' a football and rugby watching buddy scheme. See website for more details:

http://www.embracewiganandleigh.org.uk/never_watch_alone.php

In 2015 the Lancashire Friends and Sexual Relationships group successfully worked with U-Night to apply for a healthHeal People's Health Trust lottery bid for a two year project setting up a friendship and dating agency for people with a learning disability in Lancashire. More information can be found at:

<http://unightgroup.co.uk/>

How are people spending their time?

We asked people to tell us where the person they support goes for leisure activities. A full list of activities and venues people favour in the local area is in appendix 7. People go to a very broad range of venues and activities.

The most popular community venues used were eating and drinking venues, shopping, swimming, parks, cinema, bowling, college, church, cycling (including the adapted cycle scheme in Lancaster) and the SPACE Centre in Preston which is a multi-sensory environment, <http://www.space-centre.org.uk/>.

5 out of the 9 people in the survey eligible for day service support attend a day service at least once a week.

In the main people completing the questionnaire get out and about regularly in their community. There were some very positive comments about the wide variety of accessible places to go. The Friends and Relationships activities advertised in the FAR OUT Newsletter are popular with some people with PIMD. They provide a welcoming friendly activity with regular hosts and new people to meet.

"She has a wide range of activities and a very full diary of events that keep her busy and gets her out and about into the community."

Family Carer

However, others experience difficulty, mainly around using a wheelchair in smaller shops and amenities. Some activities are popular but suitable facilities are not local, for example a warm enough swimming pool with adequate changing facilities.

"He has a larger than normal wheelchair, so it only just fits in lifts. Local shops are not accessible. Many shops put stands all over the place and so it's hard to move around even in retail outlets the shops are a nightmare to move around."

Family Carer

Summary

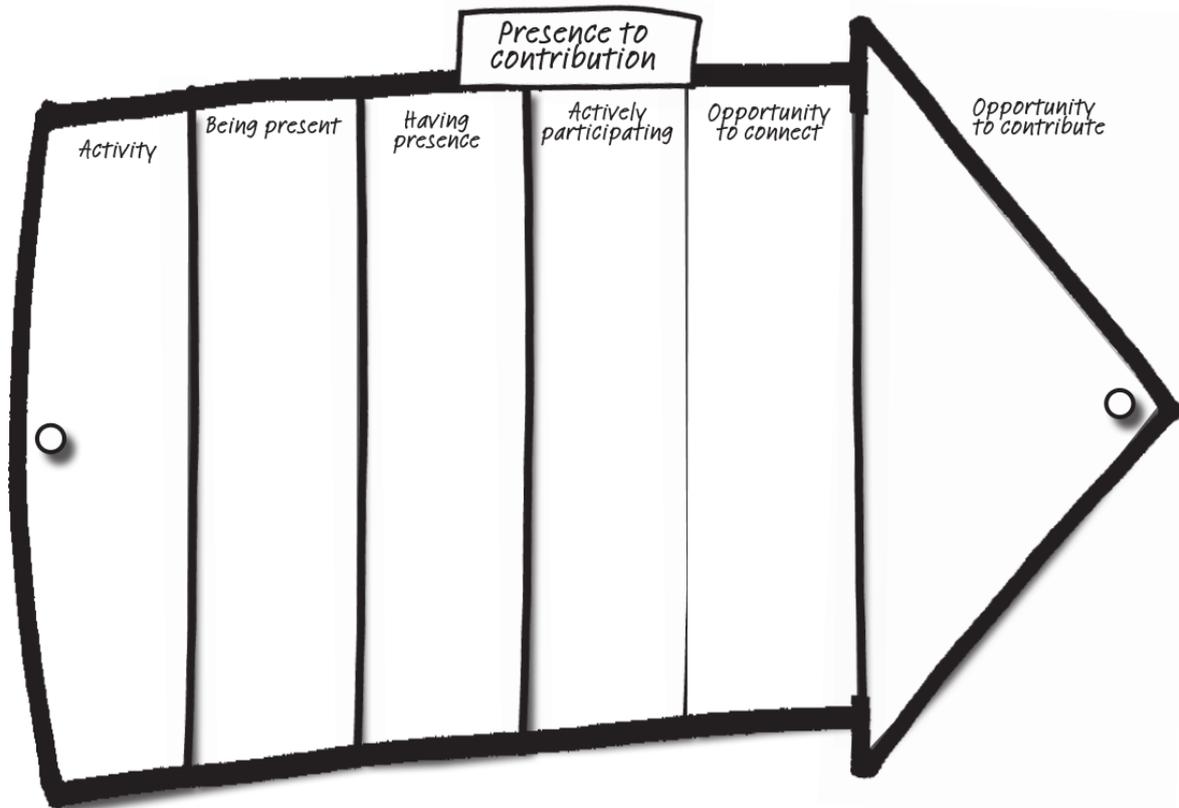
We found out that people are accessing their community for a wide range of activities. Good accessible facilities vary across the area. For some popular activities like using a sensory space or swimming pool people have to travel a long way and this can create difficulties regarding disposable income to pay for more expensive specialist activities and support hours.

Within the Mansell Report (2010) it talks about what the elements of a good service are stating that they are individualised & person centred and focus on quality of staff relationships with the disabled person (pp 8-14).

"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 (p9)

Having sound values and person centred approaches at the core of all supporters do is essential to providing good support and access to the community. Mere presence in the community does not demonstrate a good life. Supporters need to work towards every individual with PIMD actively participating in their community by looking for opportunities specific to that person's gifts and skills, enabling them to contribute to society and local life.



www.helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/presence-contribution/

Recommendations

- 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 adopt the North Lancashire PIMD Group.
- The Care Quality Commission and the Learning Disability Quality Framework will encourage providers to do the above and consider education and pathways to employment and engage in peer quality checking through the Lancashire Values monitoring scheme.

The PIMD group also endorse the **Raising our sights: services for adults with profound intellectual and multiple disabilities** (2010)

recommendations about what are the elements of a good service which enables people to access their community effectively:

- Good services are individualised & person centred
- 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)



Employment

Most people completing the survey do not do any paid work.

Valuing People Now says:

“it has to be recognised that for some people with highly complex needs, such as those with profound & multiple learning disabilities or who are medically dependent, paid employment poses particular challenges, although it remains an aspiration” (paragraph 1.5)

The Mansell Report (2010) states that employment:

"is likely to be only one of a range of activities & opportunities that adults with PIMD experience. Its value to them will be the benefits they experience from the activities & the attitudes of & interactions with those around them. The goal is that people should have the opportunity to take part in meaningful activities outside the home, including work, education & leisure." (Mansell, 2010, p28)

However, one gentleman taking part in the survey did tell us about his part time work. He is a Park Hampers Agent. Supported by staff he signs people up to a savings club. This involves collecting money from members of the public, staff and family members who agree a monthly payment. He collects 10 payments from each person then banks the money and transfers it to Park Hampers. He gets commission for this work. Each year he gives the savings vouchers to the members in November ready for Christmas.

Employment is a difficult topic as there are varying views as to whether people with PIMD can undertake paid work. Everyone has gifts and skills and therefore is capable of work if the right work and support can be found. Across Lancashire several people with PIMD have part time paid work. One person is a post and delivery man for a local company and another gentleman has his own recycling business.

Lancashire County Council supported Dolphin's Den a mentoring project open to anyone with a learning disability so that people could establish their own business or social enterprise in 2014. The North Lancashire Partnership Board firmly believes in people with learning disabilities getting into paid work and has developed

an Employment Pathway to assist people with a learning disability on their journey into paid work.

Please see the website: www.northlancsemployment.net.

Summary

When discussing employment for people with PIMD the group have received a variety of responses. One family carer commented that people with PIMD would never work. It is common for people to believe this, but we are aware of people's experiences that demonstrate with good support and determination people with PIMD can do paid work.

People with a learning disability commonly face barriers to getting paid work. They tell us that these are the common reasons why getting paid work is hard:

Loss of benefits

Lack of relevant employment opportunities

Lack of reasonable adjustments around working interviews

Lack of aspiration and expectation

Fear from family carers, paid supporters and people with learning disabilities themselves

Lack of information.

ASCOF measure 1e which is about the proportion of adults with learning disabilities in paid employment was 3% in Lancashire in 2015. This is significantly lower than the national average of 7.8% and the North West average. This rating gone down in recent years as in 2013-14 it was 4.4%.

We firmly believe at the Partnership Board and at the PIMD group that anyone wanting to work should be able to work with the right support. We want everyone who has a learning disability to have the opportunity to have a paid job and receive the benefits of paid work, not just financial benefits, but also those of having a valued role in society and social benefits like friendships and opportunities. We want people to have that aspiration and live in a community where it is common to have these aspirations for everyone.

Recommendations

- That the Government include people with PIMD in their funding for education, traineeships, apprenticeships and paid employment not

just via Access to Work but with a comprehensive programme linking Jobcentres, training providers, schools and further educations establishments via incentivising targets and quality measures. ASCOF 1e does not contain a specific measure for people with PIMD. There need to be reasonable adjustments to allow all members of society to realistically get paid work and the support they need to sustain that paid work.



Leisure & Other opportunities for involvement in the community

In the questionnaire we also asked if there is anything else the person would like to do outside the home.

People responded with these answers:

- access college courses e.g. Music, art
- go on holiday
- having more 'me' time and less group activities with housemate
- more walks for health and fun
- bowling
- swimming
- church
- discos
- cycling.

We also asked what stops people from doing their chosen activities.

They told us that funding for college courses stopped if people weren't able to show progression even if they really enjoyed it.

They told us that there is a lack of suitable Changing Places and facilities with hoists and changing areas. The Learning Disability Partnership Board has now created a Changing Places Directory which can be viewed on the new Lancashire Learning Disability Partnership Board website at this link: www.lldpb.org. We have recently had new Changing Places added, for example, at Cornerstones in Lancaster and at Enable U in Colne run by Pendle Support Services. One of our PIMD group members also attends the local Changing Places campaigning group which is run by one of our family carers and aims to lobby for more changing places. Please also see the Changing Places website for more information. On the Changing Places website you can also enter your postcode to find your nearest Changing Place: <http://www.changing-places.org/>

One problem mentioned by a few people was not having enough paid staff. For one person this meant having to go out with a housemate

which would affect where they could go. Other reasons were that paid staff were unmotivated or could not drive.

Mansell (2010) states:

"Many adults with PIMD like to take part in everyday activities in their community & there is evidence of the imaginative use of personal assistants & individual budgets to enable this. The implementation of the personalisation 'agenda' & initiatives like Sport for All & Valuing People Now will increase the range of these opportunities. It is important that in developing opportunities as part of their 'place sharing' role, local authorities ensure that people with PIMD are included." (p28)

Mansell is clearly putting the onus on local authorities to make sure people have active community lives and feel engaged and involved in their localities through creative use of personal budgets.

People told us that cost also stops activities, for example, an individual who likes cycling needs his own bike, but an adapted bike is too expensive. Mobility and physical needs are also seen as making joining in active pursuits difficult. A lack of up to date information is important as was finding community facilities to meet peoples' needs, for example, a church.

Since the questionnaires were completed a new adapted cycling scheme has been successfully established in Fleetwood at the YMCA supported by Wyre Council and with bikes bought through the Learning Disability Development Fund. The Wyre Wheels scheme has 20-25 people attending per session and 69 individuals signed up.

We asked: **What's great about your community?**

"It's great at church because of the music, the people know him, it's accessible and always friendly. It is welcoming to both him and his support. He meets friends and family and there are various social events." Paid staff

"Some places make you feel welcome and make changes to furniture and generally go out of their way to help you." Paid staff

These are the answers we received:

Two people commented that the adapted cycling scheme is great.

The Vue cinemas have good access and the seating is very good.

Carers don't have to pay as they can get a Cinema Exhibitor's Card which gives a carer free entry.

The library has a large selection of talking books and DVD's.

The availability of a multi-sensory centre.

The leisure centre has a hoist and a changing table.

The college is great for lots of people because they meet others with similar interests and skills. College helps develop 1 to 1 interaction and communication skills.

Getting out socially is seen as really important, bringing enjoyment as well as access to the fresh air.

We asked: **What could be better in your community?**

Finding meaningful daytime activities can be difficult for families and paid support alike.

"We have a very daunting task of trying to provide a full and worthwhile week for him when he leaves college." Family carer

These were the answers we received:

People would like more adapted cycling.

People would prefer to have a free cinema ticket for carers without having to buy a cinema card annually.

Several people wanted more availability of multi-sensory spaces and venues locally.

More availability of warmer swimming pool sessions with a hoist.

More support staff in the evening.

More accessible cafes, pubs, shops and libraries – access is a problem, we need ramp access and access to tables and computer terminals can be difficult. One person said "It would be great if restaurants blended food."

More 'low rider' public transport buses.

More disabled changing facilities.

One family carer commented:

"He has a larger than normal wheelchair, so it only just fits in lifts. Local shops are not accessible. Many shops put stands all over the place and so it's hard to move around even in retail outlets the shops are a nightmare to move around...Trips out are restricted...due to his changing and feeding requirements."

Individuals have regularly reported to the Partnership Board the difficulties accessing bus transport, in particular using the wheelchair space on a bus. The Fulfilling Lives group were prompted to undertake a travel survey in 2010 and you can see the full report on the Partnership Board website:

<http://www.northlancs.cswebsites.org/default.aspx?page=23648>

Some individuals using the buses were wheelchair users. People have told us that drivers will pass by without stopping if the wheelchair space is already occupied leaving people to wait at bus stops in all weathers for long periods of time. People report varying degrees of helpfulness of the driver. There are still appeals and court cases (see Your Community page 50) with bus companies to try and resolve the issue over bus drivers supporting individuals to access the wheelchair space when there are other passengers using the space.

Summary

Overall, we noted that some people are getting out and about and enjoying a very diverse range of activities in their community. Some individuals, however, struggle to find appropriate activities to do, finding staffing issues and costs prohibitive and others feel they need more information and opportunities. People are deeply concerned about how government funding cuts will affect individual's care packages, levels of support and ability to get out and about which could then impact their general health and wellbeing.

Recommendations

- To continue to campaign for new Changing Places to improve people's access to their community.
- To develop and include more activities suitable for people with PIMD 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.



Since the research was completed the Friends and Relationships Out and About group in North Lancashire have developed a Sensory Story group for adults in Lancaster Library.



This group involves librarians planning short stories and poems with props which engage listeners in an interactive way by using all the senses to tell a story.





Education

From the Mansell Report (2010):

"Since people with learning disabilities have difficulty learning further education is potentially a very important opportunity for people to continue to grow & develop. Only 14% of people with PIMD were in further education in 2003 /4. Since then, there has been a marked reduction in further education provision for people with learning disabilities. People with PIMD may have been particularly affected by a shift in priorities towards award-bearing courses & by a view that some provision is just day care rather than education." (p27)

We asked: **What's great?**

"She learns, she uses her senses and exercises. She is able to relax. She tries new things and experiences. She enjoys having lunch and coffee with other disabled and able bodied students, everybody is really friendly in the café." Family carer

College and is extremely important to people with PIMD because they are able to meet and make friends. The nature of PIMD makes it more likely to need support to maintain and not lose skills and to take longer to learn, therefore educational provision needs a lifelong learning approach. Unfortunately, carers and supporters record an approach by the education system which can alienate people with PIMD because the expectation behind the funding is that people will demonstrate progression.

Courses enjoyed and appreciated were drama, movement, music, cookery, arts and crafts.

We asked: **What could be better?**

"It feels now that people are being excluded and have little say or choice at college. There are not enough courses and variety of courses and you can only enrol on certain ones. College is one area in her life that has changed considerably over the years and for the worse." Family carer

One common problem is that there are simply not enough courses and in some localities there are no courses for people with PIMD. More variety of courses and availability is needed. Family carers have also identified there is nothing suitable in Fylde and Wyre.

One respondent recommended tasters as a good idea "because how can people know what courses they want to do unless they try them."

People completing the questionnaire said that a common problem is the enrolment process which they regard as not very good. People found enrolment confusing, not understanding when to enrol. Enrolment which ensures continuity for the individual so that they can progress each year is important. Continuity was important for quite a few people. This implies that the adult education system is not adapting to assist certain learners who may acquire skills through repetition and therefore need to access a course for longer. If courses are different each year individuals may lose out.

"Enrolment is done on a first come first served basis you could easily miss out!" Paid staff

Another problem people have experienced is courses getting cancelled. Individuals may have arranged other activities around that course prioritising the educational opportunity over other activities and arranging paid staff to support only to have the course cancelled. When finding suitable activities is already limited losing a college course can have a significant impact on a person's week.

Family carers have found that the success of the course is often dependent upon the tutor and how good they are at engaging and understanding the students; **"They could have supported him better. He was left to his own devices."**

Mansell Report (2010) states that:

"The goal should be that everyone with PIMD has access to further education which helps them grow & develop independence. New arrangements for funding further education are being implemented by the government. In order to ensure fair access to further education for people with PIMD the government should restate its policy & ask the relevant bodies to monitor their progress." (p27)

It has been noted by member of the group that in recent years with the government's austerity measures there has been a further erosion in this extremely valuable resource.

Summary

Further education for people with PIMD seems an essential part of many people's lives. Family carers and paid staff alike value the structured meaningful activity in a valued educational setting which not only provides education but also significant opportunities for both the individual and the carers to meet other like-minded people. This boosts everyone's mental well-being and keeps people stimulated and enjoying an active life. This family carer sums up their view of their task ahead and how much education is valued:

"We have a very daunting task of trying to provide a full and worthwhile week for him when he leaves college. The process of viewing what is available to young disabled adults such as he, has just started - we hope to remain positive but need lots of support to achieve a successful outcome."

Recommendations

- Colleges to 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.
- Educational establishments to have a better and clearer enrolment and re-enrolment processes and communicate them clearly to the public to ensure continuity for progress each year to enable progression and appropriate learning.
- Educational and community establishments, family carers and paid staff who support people with PIMD work together to increase the number of education opportunities 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. Carer's have commented that they find accessing college important because they meet other carers.

- Colleges work with the government to influence 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 national picture

The Mansell Report does not mention transport and the Lambeth Report (2010) recommends that "Suitable and flexible transport is provided that enables people to physically move around their community" (p40). Nationally there remains concern about changes to the Personal Independence Payment and mobility component of this benefit. People are also concerned that cuts to local councils will mean that people will lose their free bus pass. This is reflected locally and one major recurring concern of self-advocates has been access to transport and bus passes.

Many areas have a Motability Scheme <http://www.motability.co.uk/> which allows individuals in receipt of the higher rate mobility component of Disability Living Allowance or the Enhanced rate of the mobility component of the Personal Independence Payment to exchange their mobility allowance to lease a car, scooter or powered wheelchair.

The local picture

In Lancashire the NOW card provides free or cheap bus travel within the county including Blackburn and Blackpool. People in receipt of Disability Living Allowance or Personal Independence Payment can apply for a NOW Card for people with disabilities. There is also a NOW card for people of retirement age.

In 2010 the Partnership Board Fulfilling Lives Group conducted a survey of public transport in North Lancashire. 35 journeys were undertaken. The survey involved taking a bus journey and people recording their experiences. 57% of people completing the survey stated they had a mobility problem. Nine people on the survey said they use a wheelchair. One individual commented that "**There was no disabled access on the 3 buses that came.**" Another comment was that bus drivers pull away from the kerb before people have got settled on the bus. There was an interesting mix of responses regarding the helpfulness of the driver when a person using a wheelchair got on the bus. Some were happy to help and others did not help at all for example one person actually had to ask the driver to pull close to the kerb and get the ramp out. Mostly people felt positive about the bus service they received. You can see the full report on the Partnership Board website:

<http://www.northlancs.cswebsites.org/default.aspx?page=23648>

Thirty-one people responded to this question. Out of these thirty-one:

Fourteen people use more than one mode of transport.

Three people have their own car.

Eighteen people have a car on the Motability Scheme.

Seven people use taxis.

Ten people use buses.

Seven people use a family car.

Six people use train travel.

Two people use Lancashire County Council passenger transport.

Two people access hospital transport.

One person uses a hire car.

One person uses trams.

One person uses their paid staff's car.

For the majority of people only using one mode of transport, this is generally their own car, a Motability car or their family car. One person uses only taxis for all their journeys.

We asked: **What is great about transport?**

"She needs a mobility car to enable her to get around to do all her activities for her engagement. This helps to stimulate her and acts as a form of exercise and aids her well-being."

Paid staff

"We can go when we want and where we want."

Paid staff member commenting about the importance of the individual having their own car.

People told us that having their own accessible or adapted vehicle was important to them. The top reason for this was the freedom it brings. Another important reason was the way the vehicle can be adapted to suit the individual's needs. People really value the Motability Scheme and say that it is a really good service. It enables flexibility and freedom for both the individual and family carer.

One particular reason people like having their own transport is to go on days out and go to nice places to which you cannot get on public transport. This is key because a person may have chosen places they like to go because they love the activity, have good access or a Changing Place. Some suitable venues would be too complex and difficult to arrange public transport and with reference to the comments made about wheelchair access on the buses a long journey could prove very difficult to arrange.

Taxis are also an important mode of transport for people with PIMD. Some are accessible with a ramp. Some people still use taxis even when they have their own adapted vehicle. This could be because not all their paid support can drive.

People responding also use trains and are happy with the service they receive.

Individuals also use hospital transport to access healthcare.

People like the accessible buses because you don't have to book them in advance which gives people more freedom and they are easy to get on and off. Some carers do not drive and depend on the accessible buses to get out with the person they support. This is particularly relevant for people living in rural parts of North Lancashire.

The travel card gives free or discounted travel on buses and offers people another mode of transport if they don't have paid supporters who can drive.

Public transport is seen as essential and much improved in recent years. In North Lancashire the buses, trains and trams are all accessible. One paid staff member comments:

"On the buses, trains and trams the public are a lot more accepting and welcoming to people with disabilities."

Fylde and Wyre

We asked: **What could be better about transport?**

The responses were:

"There are very few wheelchair accessible taxis. We have to book in advance which is not always possible due to health."

Paid staff

"The cost of petrol!"

Paid staff

"Not all paid staff are drivers. This limits the person's ability to get out and about and is not cost effective for the individual."

Paid staff

Some people have struggled to get insurance for their Motability car to insure several drivers. People are concerned about changes to this type of insurance making it prohibitive to have more drivers on the insurance. The cost of fuel has also become an issue for a few people.

Some accessible vehicles are larger than standard cars so access to car parks has been a significant concern for some people. Another problem is people parking too close at the back of the accessible vehicle so that the person cannot get back into their vehicle.

One cost saving solution was suggested by a paid supporter:

"Rules for shared use of a disability car could be introduced. It would be easier if the paid support could apply for a shared Motability car so any of the people living together could use it at any time instead of it having to belong to one person." Paid staff

Several people mentioned that not all buses are wheelchair accessible and there need to be more spaces for people who use wheelchairs on buses and more accessible buses. (See **Your Community** section)



One individual has to regularly wait for the next bus when the wheelchair space is already occupied. Another issue with buses is that a known route will have accessible buses, but as a one off sometimes a bus arrives which is not accessible. This means the person has to wait for the next accessible bus or miss out on their activity. The law now requires

every bus which carries more than 22 passengers to be accessible. Both the 2010 Transport Survey and the PIMD Questionnaire point out that one problem is that the space for the wheelchair is often blocked by a pushchair or pram. This has been a consistent problem and was recently raised at a national level when an individual took a case to court when he found he could consistently not use the wheelchair space due to prams and pushchairs using the space. In September 2013 an incident where the driver would not request that the pushchair was removed from the wheelchair space was considered to be unlawful discrimination in breach of the Equality Act 2010 which applies to all transport providers. First Bus was ordered to change its policy, however, since this a new ruling has occurred regarding Arriva North East Ltd bus company which undermines the ruling regarding First Bus. Both companies have applied to the court of appeal and bus companies are not willing to change their policies until a conclusion is reached.

For some people living in rural districts there is no bus service which means they are reliant on expensive taxis. Rural bus services are often limited. If these services are reduced or cut people's ability to engage in their local community, work or join events becomes very limited.

Trains

When going on a train one problem identified was that the wheelchair ramp was not always ready.

Taxis

Some taxi drivers do not use their equipment safely and one person has experienced an accident as a result of this.

Summary

Transport is of vital importance to people with PIMD offering access into the community. Some people have their own cars, others are heavily reliant on public transport or taxis. Most people use a combination of transportation, often using buses, taxis and trains regularly. Some people who have their own car also use public transport. Sixty-eight percent of respondents have their own car, the majority via a Motability scheme accessed via Disability Living Allowance and Personal Independence Payment.

The PIMD Group have also observed that government funding cuts have affected the local authority funding for subsidises on public transport. Some people are reliant on public transport to access their community

facilities and these funding cuts will affect their access and mental health and wellbeing.

The group have also been made aware that certain wheelchairs purchased by the health authority from specific wheelchair companies have not been crash tested for use on public transport. Therefore, due to insurance limitations and risk assessments this is significantly limiting individuals' ability to access public transport and a full life.

Recommendations

- That 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 and PIMD awareness and communication.
- That Health authorities only purchase wheelchairs that have been tested to high standards enabling individuals to access all forms of public transport using their wheelchair.



Housing

The national picture

In 'Raising Our Sights' Mansell (2010) outlines the difficulties faced by people with PIMD and their families in accessing adequate housing within the options of housing provision available. The report highlights the fact that people with PIMD require more costly packages because of the extra space, insulation, equipment and shared and private spaces, with no additional funding available to provide for these requirements.

In the 2008 Emerson & Hatton report for 'People with Learning Disabilities in England' it notes that 64% of people with profound multiple learning disabilities live with a family carer, while 19% live in a residential care home, the remaining percentage living in other accommodation like NHS accommodation.

The local picture

People with more complex needs face a range of challenges when accessing housing. Aids and adaptations, lifts, flat access and more space are often required and sometimes suitable housing stock is not available. Housing is available in the private sector, through housing associations and the councils. Each local council has its own housing plan which will address different people's needs. (See appendix 8 for the example of the Lancaster City Council Housing Plan). However, they are not legally required to provide adapted housing for people with PIMD. Finding a house or flat mate could provide a challenge, while another thing to consider is a person's individual budget and the type of support needed.

Through the questionnaire we found out that:

9 people were living in the family home.

5 people were living in a residential home.

21 people were living in supported living or their own tenancy.

We asked: **What is great about housing?**

Comments from family members caring for the person in their own home included:

“Our house has been adapted for him but was hard before the adaptation.”

“He enjoys his own home environment and the security of living with his parents.”

“This is where she is happiest and really settled. Things work at the moment because of amount of care and because both parents help and are well.”

When asked: **What could be better** family members caring for the person in their own home said:

“More room! It’s hard with all his equipment, feeding pump, feed bottles, medication, oxygen, nebulizer, chairs etc. The house seems more like a hospital at times!”

One person reported the difficulties experienced looking for a supported living scheme for their family member, with one noting that four offers of accommodation within a supported living scheme had fallen through with no explanation given. Another suggested that if the person with PIMD could ‘go on’ the rent card, regardless of whether they could sign it, there would be more security for both the person with PIMD and the family.

Of the others living in their own tenancies, supported living schemes or dwelling in residential homes, the same question was asked: **What is great?**

Positives included being happy with the people they share with, being close to family, the house being adapted to meet the person’s needs, easy access to exits, having a large, safe garden, having a large detached house, located in a nice quiet area and being close to facilities.

We also asked: **What’s not great about housing?**

Responses included that housing could be better adapted to meet the person’s needs. Many commented on the difficulties with staffing levels leading to the person not getting enough support to go out. Others experienced negativity from neighbours and community facilities in the local area being limited.

Summary

It seems that the most important housing issue for people is the security in the relationships with the people they live with (whether this be relatives or friends), the level of adaption made in the house to meet their needs, the location of the property and proximity to facilities and space. When these factors were in place, the housing situation was described as 'great'.

Recommendations

- Local councils and other relevant organisations to 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 how funding can be obtained for adaptations, etc. For local councils to provide range of property that is fit for purpose to choose from.
- Local housing associations and housing companies across Lancashire to do a housing needs 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.
- For families across Lancashire to be supported to find funding for aids and adaptations to help people's lives to be easier and more comfortable.
- There should be a change to the law to allow people who do not have capacity to have a way of holding a tenancy agreement still have access to full benefits and tenancy rights.
- Reference should be made as appropriate by the Transforming Care programme and social and health care teams when looking to

move individuals with PIMD back to their communities from long stay institutions to these recommendations, government guidance and good practice documentation.



Benefits and Money

The national picture

The Lambeth Report (2010) describes many family carers of people with PIMD struggling to get information about benefit entitlements.

Nationally, there has been a huge outcry regarding the changes to benefits for people with disabilities. The government announced that it wanted to make savings by making changes to benefits under the



Welfare Reform Bill in 2011. Disability activists argued that the proposals would unfairly penalize sick and disabled people. The Hardest Hit campaign united people with disabilities to challenge the cuts. Their coalition is made up of over 90 disabled people's organisations and charities.

Not only is the majority of the benefits system due to change but people with disabilities seem to be bearing the brunt of a lot of the changes. For example, changes are being made to Disability Living Allowance. This benefit will become the Personal Independence Payment for people of working age and its structure and payments will be different, keeping the mobility and care components, there will now be only two levels.

Alongside this, changes to Housing Benefit have left people with PIMD particularly vulnerable to the single room subsidy or 'Bedroom Tax' as it's commonly known. This means that where a property is deemed 'under occupied' the eligible rent is reduced by a national percentage. For example, this meant that in Lancaster 679 households had their benefit reduced due to this change. (Figures from DWP 6th November 2013.)

The government announced that the Independent Living Fund (ILF) would end in December 2013. ILF provided money to help disabled people live an independent life in the community rather than in residential care. In 2013 five people with disabilities challenged the decision and a reprieve for this allowance was granted by the Court of Appeal in November 2013. Clive Coleman BBC legal correspondent reported:

"The Court of Appeal unanimously quashed the decision to close the fund and devolve the money, on the basis that the minister had not

specifically considered duties under the Equality Act, such as the need to promote equality of opportunity for disabled people and, in particular, the need to encourage their participation in public life." BBC News Website 17/1/14 <http://www.bbc.co.uk/news/uk-politics-24834558>.

However, since then it has been announced that the Government plans to close the Independent Living Fund on 30th June 2015 and transfer responsibility for meeting the eligible care and support needs of current ILF users to local authorities in line with their statutory responsibilities.

The local picture

Locally individuals have not reported significant problems with these changes because at the time the questionnaire was undertaken the benefit changes had not been rolled out. However, local people with learning disabilities, their family carers and paid staff are concerned about the changes and have asked for benefits to be a standing agenda item at the Partnership Board. The North Lancashire Partnership Board received regular updates from colleagues from the Department of Work and Pensions and the Lancashire County Council Welfare Rights Service.

The Questionnaire

Out of 35 people replying to this question 20 people said they receive benefits. People told us that support workers and family members help people manage their weekly budget, benefits and money. Some people enjoy going the bank to collect their money. One paid staff member said that the benefits run smoothly and there are no issues getting entitlements.

What could be better?

The major observation from the questionnaire is that people want more information and advice about benefits. Some people said they have never had any advice and that information is not readily available. A family carer wanted more straight forward information and found the benefits system too complex. One person said "you are relying on other people in the same situation to tell you".

One family member asked for "**More trained staff that are capable of dealing with disabled people and their families.**" This family carer was not alone as other supporters wanted benefits explaining better.

Summary

Generally people want to know what they are entitled to and want to know where to get help, up to date information and advice about benefits. Complaints were made that forms are often repetitive and long. Family carers want benefits to help make life easier for the person they support. Quite a few people were happy with the benefits they receive. There is a threat to local Welfare Rights services which are run by the local authority. This is a key place where people go to get support. Family carers said that support is essential to them particularly around the time of transition but is valuable to all family carers. It is a major concern that organisations like Welfare Rights and Citizen Advice Bureaux are at high risk of closure leaving people with no one to turn to help them navigate the very complex welfare benefits system.

Recommendations

- 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 and letters concerning benefits are changed so that they are more accessible and in easy read and plain English
- That organisations like Welfare Rights and Citizens Advice Bureaux are considered essential services and retained
- 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

The national picture

The Lambeth report (2010) describes many family carers of people with PIMD struggling to get information, such as details about local services and how to manage direct payments, all of which they need to support them in their caring role. The report suggests that if families are getting good, relevant information, it is through carer networks rather than through statutory services.

The local picture

In North Lancashire we are finding evidence that family carers and paid staff are struggling to access the information they need to support them in their caring role. The Partnership Board support a Family Carer Network which is supported by the Community Engagement Officer employed by Lancashire County Council. Through consultation with family carers a news bulletin was used to keep family carers in North Lancashire up to date on national, regional and local information, activities, changes, government information, consultations and social care. Family carers were also invited to information workshops on such topics as positive behavioural support, person centred approaches, managing difficult situations, carer's rights and matching support.

What people told us

“We don't have a social worker, we found (having a social worker) helpful for advice.” Family carer

“I wish the (people we support) had an individual social worker...”
Paid carer

Shortly before the questionnaire went out Lancashire County Council restructured Adult Social Services resulting in the team of social workers with a learning disability specialism (and co-located with the learning disability health teams) becoming generalists and moving to a different location. This change resulted in social workers with no former experience in learning disability being allocated to people with extremely complex needs for brief episodes of care. People are consistently telling us that they are struggling because they no longer have an experienced, specialised, named social worker.

"Restructuring at Social Services is not great. We have had no contact with the Social Worker or feedback since last year. The new system is isolating." Family Carer

Rather than having steady input from someone they have an established relationship with, people are finding they cannot even access a social worker to ask questions or get information. Family carers in particular find this distressing and unhelpful. Just knowing that they can contact someone makes a huge difference to their peace of mind and general well-being when they are undertaking a complex caring role. This can also result in people missing out on funding that they are entitled to:

"(Information) needs to be clearer as we lost out on benefits...for 3 years, as we did not know we were entitled, and benefits agencies did not volunteer the information."

Family carer

One family carer cited Welfare Rights as a useful source of information, while others said that their provider's staff team were good at providing information.

3 paid staff reported they get good advice from the local learning disability health team, with one paid staff member citing an advocate as a good source of advice.

It appears that although some respondents felt that they are able to access good quality, timely information and advice, there are others who feel they are not being given information they need and are not sure where to access it from.

"I don't know how to get the information I need and I don't feel I am getting the information I need. The information I receive is not helpful." Paid staff

Another paid staff member suggested:

"We could do with a national Directory about Services available for people with mobility problems, learning difficulties, activities and holidays."

"We would like to be able to benefit from more assistance for medical, advice and help with social aspects. Help with equipment."

We feel we are not getting enough input from the services that we do receive."

Family Carer

Summary

Although many respondents did appear to be satisfied that they had received good advice or knew where to go to access it, there were many others who found it difficult, especially when the advice needed was linked to funding or benefits. Comments around social care support criticized the move to generic social work teams citing poorer support during social care assessments and lack of continuity which is vital for people with PIMD due to the complexities of their lives and high support needs.

In late 2015 Lancashire County Council announced it would return to having specialist learning disability social care teams. This news was greeted with great relief by members of the community.

Recommendations

As recommended in the Lambeth report (p.52) and in line with the 2014 Care Act 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, personal budgets and carers' assessments. 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, including 'hidden' 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.

Summary of Recommendations

This summary report draws conclusions from the questionnaires sent out in 2012, the Mansell Report (2010) and from members of the PIMD Sub Group. It 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. This could be done through staff training or by sharing documents like the below:

https://www.improvinghealthandlives.org.uk/uploads/doc/vid_11332_Reasonable%20Adjustments%20for%20PWL%20easy%20read%20final%20compressed.pdf

http://www.improvinghealthandlives.org.uk/uploads/doc/vid_10118_IHaL%20NHS%20Trust%20Reasonable%20Adjustments%20survey%202010.pdf

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

Communication Passports

What are they?
A communication passport explains how an individual communicates, for example, how they show they are happy, they don't like something or they are in pain. These are crucial documents to help form decisions around whether the person can consent to a particular decision.

What do they look like?
A passport can take a variety of different forms: small booklets produced on a computer, songbooks with picture cards, 'Talking Photo Albums' (with programmable sound bytes), CD-ROMs and even apps for tablets! It doesn't matter which method is used, as long as it captures the information about that person's communication that is needed to form a relationship.

What do we do with them?
A passport belongs to the person. They are living documents—people change and the passport will change too to reflect this. Communication develops over time and the passport will help structure this and capture progress.

Who is it for?
Communication passports are particularly helpful for people who have difficulty communicating in a conventional way and may have developed a number of ways to express meanings that are personal to them.

Who can put it together?
The passport is put together with the person by anyone who knows the person well such as family members or paid carers. Training sessions are delivered throughout the year in North Lancashire. Support can also be accessed from the local Speech and Language Therapy service, see over for details.

- Family carers are informed about Annual Health Checks, reasonable adjustments, Health Action Plans, Hospital Passports, Communication Passports, assistive technology, rights for carers and what training is available to them regarding

these. For example, sharing short information sheets on each of these subjects, offering workshops for family members and supporters through the PIMD Sub Group and/or the Learning Disability Health Teams.

- 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. 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.
It is a primary care responsibility to offer a Health Action Plan at the Annual Health Check.

Primary Care and Lancashire Care Foundation Trust work with health colleagues towards a quality measure to ensure Health Action Plans are being developed with people and check they are impacting health outcomes.

- 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
- Family members understand the importance of Hospital Passports 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 by all health and social care providers 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.
- Training in how to communicate effectively, including using person centred approaches, with people with PIMD should be available for all; including, for example, paid staff, universal service and medical

staff. For example, through training medical students via the PIMD Champions and Sub Group; through using local organisations like Learning Together North West and S.A.I.L. who deliver training using experts by experience.

<http://www.learningtogethernw.org/index.html>

- 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.
- Care pathways should be established to ensure the person's health needs are co-ordinated when they access services.
- All medical and social care staff are given comprehensive training in the Mental Capacity Act with annual updates which enables them to competently apply their knowledge around the Mental Capacity Act.
Having a quality measure around competence will assist this and having local experts in using the Mental Capacity Act and in making Best Interests decisions. For example accessing the non-instructed advocacy service:
<http://www.blackpooladvocacy.co.uk/ni-advocacy.html>
They would be able to offer support, expertise and advice to anyone with PIMD needing to support a decision under the Mental Capacity Act.
- 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 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 shared with other relevant individuals, including family carers. For example:
<https://www.mencap.org.uk/posturalcare>

- 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.
- Information about continuing health care and personal health budgets should be accessible and give clear guidelines around who is eligible.
- Schools, colleges and education establishments need to be responsible for educating families and supporters, as part of the transition from their establishment, in the importance of continuing to use any equipment.
- The local NHS Health Trust should address the inequalities relating to access to specialist allied health professionals across the whole of Lancashire
- 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

The recommendations in the **Mansell Report** (2010) regarding wheelchairs are excellent. The PIMD Group agree with these recommendations and would like to see the government accomplishing them 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 (e.g. '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.



Communication

- Training in communication methods and in developing communication passports need to be regularly available to all paid staff and families.
- More information should be 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.
- 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 including communication aids if bought for the individual and not the school.
- Providers and health professionals should organise regular events for sharing good practice around communicating with people with PIMD to help paid staff and family carers share positive stories.



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 interest decision making.
- 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. This could be achieved via adult social care and providers hosting an annual assistive technology event.



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 adopt the North Lancashire PIMD Group.
- The Care Quality Commission and the Learning Disability Quality Framework will encourage providers to do the above and consider education and pathways to employment and engage in peer quality checking through the Lancashire Values monitoring scheme.

The PIMD group also endorse the **Raising our sights: services for adults with profound intellectual and multiple disabilities** (2010) recommendations about what are the elements of a good service which enables people to access their community effectively:

- Good services are individualised & person centred
- 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)



Employment

- The Government include people with PIMD in their funding for education, traineeships, apprenticeships and paid employment not just via Access to Work but with a comprehensive programme linking Jobcentres, training providers, schools and further education establishments via incentivising targets and quality measures. ASCOF 1E does not contain a specific measure for people with PIMD. There need to be reasonable adjustments to allow all members of society to realistically get paid work and the support they need to sustain that paid work.



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 and government 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.

- Educational establishments have a better and clearer enrolment and re-enrolment process and communicate these clearly to the public to ensure continuity for progress each year to enable progression and appropriate learning.
- Educational and community establishments, family carers and paid staff who support people with PIMD work together to increase the number of education opportunities 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 work with the government to influence 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 and PIMD awareness and communication.



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 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 across North Lancashire are consistently supported to find funding for aids and adaptations to help people's lives to be easier and more comfortable.
- Local housing associations and housing companies across Lancashire to do a housing needs 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.
- Reference should be made as appropriate by the Transforming Care programme and social and health care teams when looking to move individuals with PIMD back to their communities from long stay institutions to these recommendations, government guidance and good practice documentation.
- There should be a change to the law to allow people who do not have capacity to have a way of holding a tenancy agreement still have access to full benefits and tenancy rights.



Benefits and Money

- The Department of Work and Pensions improve their support to people with disabilities and their families by training their staff in disability awareness and disability benefits.
- Information and letters concerning benefits are changed so that they are more accessible and in easy read and plain English.
- 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), and in the **Care Act 2014**, 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 personal budgets and since the Care Act in 2014, advocacy when assessing people's care needs. This should include:

- awareness about what direct payments and personal budgets are
- making sure people understand the benefits of direct payments and personal budgets
- ensuring family carers, including 'hidden' 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 personal 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.

What has happened since the survey? "You said, we did"

The report shows that people with PIMD, their families & carers face immense challenges each & every day from going to the toilet to communicating their wants to their supporters. There are some pockets of good practice locally mainly achieved by the endeavours of dedicated people. These include Changing Places, local adapted and wheelchair bicycle schemes, an information leaflet on communication passports, Friends and Relationships events, groups, newsletter and Facebook page, Staying up Late campaigns and participating in the Learning Disability Partnership Board to ensure the 'voice' of people with PIMD is heard at all levels. The Lancashire Learning Disability Self-Assessment Framework has consistently delivered green results for its Living Well category encompassing life in the community.

As a result of this research the PIMD group have established a team of family carers and academics who train medical students, doctors and nurses on a regular basis at two universities in the local area. The training has been devised by the group with the assistance of the speech and language therapist and local provider colleagues. The family carers input their personal experience. The training includes sections on communication and posture and included video footage. The group are now planning to train social work teams across the county.

The PIMD group have also established easy read information leaflets about Communication Passports. (See Appendix 11).

The group have been engaging with their local MPs and Clinical Commissioning Groups and lobbying for improved services.

They have been writing to local supermarkets to influence their building strategy to include Changing Places in all new supermarkets locally.

The group are now proposing to work to the new Lancashire Learning Disability Partnership Board and continue the fantastic work they have achieved to date.

Conclusion

The questionnaire undertaken by the North Lancashire Partnership Board PIMD sub group was to find out more about the population of people with PIMD in North Lancashire in order to influence and improve the services of this very specific minority group who generally do not have a strong 'voice'. They are a passionate group who want people with PIMD to have a say at Partnership Board and service level. They also aspire to influence national and international policy and practice. *Valuing People* (2001) and *Valuing People Now* (2009) clearly state how important it is for Partnership Boards to co-produce their work with all people with a learning disability including people with complex needs. This group have achieved this by working hard to elicit the views and experiences of families and supporters.

This report summarises the findings and concludes that there is some good practice and good services supporting people with PIMD across North Lancashire. They also discovered through the views of family carers and people who directly support people with PIMD that some services need improvement as seen in the recommendations. This information alongside the national research mentioned in this report demonstrates the need for particular attention to be paid to the support and services of this group of individuals and in particular health services.

The PIMD Group have achieved their remit of influencing and improving services. This report touches on some of the good work they have achieved by working on the information they collected. They continue to champion the cause of people with PIMD and are looking forward to working with the new Lancashire Learning Disability Partnership Board.

The PIMD Group members have been an inspiration with regards to their tenacity, patience, ingenuity and willingness to tackle any task required to see people's lives improved and changed for the better. We look forward to sharing this report with partners and stakeholders at all levels locally, regionally, nationally and internationally to influence positive change for people with profound intellectual and multiple disabilities.



Amanda Topps
Community Engagement Officer
Lancashire County Council
May 2016

Resources

PIMD information sheets (see Appendix 11)

Assistive Technology www.lancashire.gov.uk/health-and-social-care/adult-social-care/further-information-and-advice.aspx#Equipment

<http://www.inclusive.co.uk/>

Link to hospital passport, info about AHC, dentist passport, health action plan [http://www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets))

Communication Passports: www.communicationpassports.org.uk

PCP tools: <http://ormerodtrust.org.uk/pcp-tools/>

PMLD network: <http://www.pmldnetwork.org/>

Mencap e.g. Involve Me; <http://www.mencap.org.uk/what-we-do/our-projects/involve-me/resources-involve-me>

Human Rights: <https://www.equalityhumanrights.com/en/human-rights/human-rights-act>

Human Rights for Carers: <https://www.bih.org.uk/carersguide>

Carers UK: <http://www.carersuk.org/>

Mental Capacity Act Code of Practice:
<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

An Ordinary Life; supporting families whose child is dependent on medical technology or has complex health needs, Foundation for People with Learning Disabilities, May 2012.

Employment website www.northlancsemployment.net/

Advocacy Access 0345 456 3210
www.advocacyaccess.org.uk

The Advocacy Access website is now live to search for advocacy services in Lancashire and Blackburn with Darwen. Funded by Lancashire County Council and Blackburn with Darwen Council, the

'Advocacy Access' helpline is a single point of access, staffed by specialist workers that can help direct you to the right service to be heard with any NHS or social care related issue or complaint.

This service is now available online. Simply go to our 'find help page' on our website: www.advocacyaccess.org.uk type in details of your issue and your location. This will direct you to organisations that could provide you with advocacy support.

The single point of access will help you to:

- save time, by putting you in touch with the right service
- understand the type of support available and whether it can help you with the issues you want to address
- understand whether you have a right to advocacy by law if you lack capacity or have a mental health condition
- get involved in advocacy through voluntary work or training.

Acknowledgements

Sincere thanks to the PIMD Sub Group members and people with disabilities who kindly took part alongside their family carers and supporters. The information you shared was invaluable.

Special thanks also go to:

David Grundy, Chair of the PIMD sub group of the North Lancashire Learning Disability Partnership Board

Lynette Ashton, family carer and PIMD Champion

Family carers who completed the questionnaire

Paid staff who completed the questionnaire

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Index of Appendices

PIMD Questionnaire "Tell it as it is..."

Questionnaire letter to participants – there were two versions for the two districts.

- 1. Terms of Reference from the PIMD Sub Group**
- 2. Recommendations from 'Raising our sights: services for adults with profound intellectual and multiple disabilities' A report by Professor Jim Mansell, March 2010**
- 3. Extract from People with Learning Disabilities in England
Eric Emerson & Chris Hatton
CeDR Research Report 2008:1
May 2008 pp2-5**
- 4. Extract from Lancashire Multi-Agency Carers Strategy 2013-15
pp1-12**
- 5. Carer's Allowance**
- 6. Conclusions and recommendations from the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities, 2013**
- 7. Your Community - How are people spending their time?**
- 8. Excerpt from the HOUSING ACTION PLAN 2012 – 2017
Lancaster City Council November 2012 pp41-44.**
- 9. The PIMD Group discussed questions at their meetings to take to the Specialist Mobility Rehabilitation Centre in Preston on 3 October 2013.**
- 10. Lancashire Communication Checklist with Glossary of Terms**
- 11. PIMD Communication Passport Leaflet**



"Tell it as it is..."



A survey of the experience of people with Profound Intellectual & Multiple Disability their family carers and supporters

Please tick the boxes where applicable. If you want to add extra information and run out of space please use additional pages. Please return **in the SAE** or to **Amanda Topps** at The Knoll, Westbourne Road, Lancaster, LA1 5EF **by 30th April 2012**

Some of the questions may not be relevant to you and the person you support, please leave these questions blank.

1. Health and Well-being

Includes: information & advice, annual health checks, health action plan, communication passport, hospital passport and any other aspect of health care

The government has arranged that all adults with a learning disability (including people with a profound intellectual and multiple disabilities) can access an **Annual Health Check** through their GP.

Does the person you support / family member access this?

Yes No Don't Know

If No please explain why:

Please tell us about your experience of the health check, good or bad

Does the person you support / your family member have a Health Action Plan?

A **Health Action Plan** is the person's document with actions written down to make sure the person keeps healthy.

Yes No Don't Know

If Yes, please explain how it has helped or what could be better:

Does the person you support / your family member have a Hospital Passport?

A **Hospital Passport** is a document with important information written down about the person to make sure they keep healthy, safe and happy during a hospital stay.

Yes No Don't Know

If Yes please explain how it has helped or what could be better:

If you don't use the above documents, what do you do to help medical staff provide good support?

Please tell us about it:

Does the person you support / your family member have a Communication Passport?

A **Communication Passport** is a document which details how best to communicate with the person.

Yes No Don't Know

If Yes please explain how it has helped or what could be better:

If the person doesn't use a communication passport, please tell us how they communicate with others:

Health Issue Please write the health issue in this column	What's great? Example Catherine enjoys hiring an adapted bike because she likes to feel the wind in her face and she enjoys the fresh air and exercise When we visit the hospital staff ask us for our hospital passport and always refer to it when providing care	What could be better? Example Trips often have to be cut short due to lack of appropriate facilities to attend to her personal care needs. We need a Changing Place nearby. When we visit hospital they do not have a hoist ready to manage transfers. There needs to be a better system in place for appointments.
Physical Health (including sight and hearing)		
Health Issue	What's great?	What could be better?
Mental Health		
Dental needs and oral hygiene		

Mobility needs, transfers and postural support		
Communication		
Continence		
Health Issue	What's great?	What could be better?
Diet and exercise		
Eating and drinking		

issues		
Other		

If you are a paid carer/supporter please go to Question 4.

2. Support for unpaid carers

Including statutory services and support groups for carers

The Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 give a right to a separate assessment for people of any age providing a substantial amount of unpaid care on a regular basis to ill, elderly or disabled persons who are seeking help from adult social care services.

If you are an unpaid carer have you had a Carer's Assessment?

Yes

No

What's great?

What could be better?

3. Respite and Short Breaks

Includes statutory services, family support, quality and quantity of support, etc

Does the person you support have short breaks/respites?

Yes

No

What type of short break do you use most frequently:

What's great?

What could be better?

4. Your Community

Includes leisure centres, places of worship, cinema, libraries, shops, cafes, pubs, parks, retail outlets, entertainment, etc

If you need more space please add an extra sheet

Where does the person you support go?

Please list venues and places:

What's great?

What could be better?

Is there is anything else the person would like to do outside the home?

What stops them from doing it?

Please tell us about any **access** issues you have:

5. Employment and day activities

Includes paid work, work experience, voluntary work, apprenticeships, day services, support to get employment, etc.

If you need more space please add an extra sheet

If the person is involved in any of the listed activities or others please specify below:

How many hours a week?

What's great?

What could be better?

6. Education and training Includes courses at schools, colleges and in the community	What has the person you support accessed?	What's great?		What could be better?

7. Transport

Please tick all that apply:

- | | | | |
|--------------------------|--------------------------|-------------------------------------|--------------------------|
| The person's own car | <input type="checkbox"/> | Travel care LCC passenger transport | <input type="checkbox"/> |
| Car on Motability Scheme | <input type="checkbox"/> | Dial a Ride | <input type="checkbox"/> |
| Taxi | <input type="checkbox"/> | Hospital Transport | <input type="checkbox"/> |
| Public transport bus | <input type="checkbox"/> | Family car | <input type="checkbox"/> |
| Rail | <input type="checkbox"/> | | |

Other (please specify) _____

<p>If you need more space please add an extra sheet</p>	<p>What's great?</p>	<p>What could be better?</p>
<p>8. Housing</p> <p>Think about choice of accommodation, access, information and advice, home ownership</p> <p>Please use a separate sheet if you need more room.</p>	<p>What's great?</p>	<p>What could be better?</p>

<p>9. Benefits</p> <p>Includes help you get to access benefits, forms, information and advice, how benefits work, how you receive benefits</p> <p>Do you feel you are getting the information you need?</p> <p>Is the information you receive helpful?</p>	What's great?	What could be better?

10. Information and advice

Includes information and advice you might get from advice centres, telephone help-lines, advice from specialist teams and agencies

Do you know how to get the information you need?

Do you feel you are getting the information you need?

Is the information you receive helpful?

What's great?

What could be better?

11. Specialised Equipment

Includes assistive technology (this may include things like an epilepsy sensor, a call alarm system or big mac button for example), night time positioning systems, special arm chairs, spinal supports, boots & callipers, standing frames, wheelchairs/special seating, tracking & hoists, etc

What specialised equipment does the person you support use?

What's great?

What could be better?

12. Other	What's great?	What could be better?
<p>This includes anything you want to make a comment on but does not fit into any of the other categories</p> <p>Please use a separate sheet if you need more room.</p>		

Please return this survey in the SAE or to: Amanda Topps by 30th April 2012. If you would rather talk to us please ring Amanda or join us on 26th April, see attached letter for details.

Thank you very much for taking part. Please keep in touch by giving us your details on the attached letter. Don't forget to tick the boxes if you want more information about the things mentioned in the survey.

Tel: (01524)
Fax: (01524)
Email: Amanda.Topps@lancashire.gov.uk

Your ref
Our ref
Date

Dear * Person's Name* Family Carer or Supporter

People who organise learning disability services in Lancaster, Morecambe Fylde & Wyre have nominated a group of people to carry out an information gathering exercise. They want to learn about things which are working well for people with profound intellectual and multiple disabilities and those supporting them and the difficulties and problems they may face.

What does Profound Intellectual and Multiple Disabilities (PIMD) mean?

Some people use the term complex needs or profound multiple learning disabilities.

For the purposes of the survey 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.

Why we are contacting you

We think the person we have addressed the letter to may have a profound intellectual and multiple disability. Please consider the description above and if you feel the person does fit the definition we would like to ask you to take part in the survey.

If you are an unpaid family carer and do not live with the person named on the letter you should be aware that a survey is also being sent to their home address so that their paid supporters can complete it with them. We really want to hear your views and experiences as their relative too, so we have sent you a copy to complete as well if you wish.

There are three different ways you can take part:

- **Fill out** the survey and **return in the enclosed SAE** or to **Amanda Topps by 31st March 2012**
- **Phone** Amanda Topps on 01524 586182 and arrange for someone to meet you so that you can share your views
- **Come and meet us at** our coffee morning at the Training Room at **Lancaster Disability Service, Thorpe Avenue, Torrisholme , Morecambe, LA4 6NG (Thorpe View) on Tuesday 6th March 2012.** Drop in to see us and meet some other family carers between 9.30am and 12pm, have a coffee and cake and talk to us about your views and concerns.

Why we are asking these questions

The survey covers questions relating to the person's health and well-being, support for unpaid carers, community leisure activities, employment, housing, information from various sources, specialised equipment, education and transport. We are asking these questions so that we can think about people's everyday lives, things to celebrate and problems they may face. We would like to find out where particular improvements can be made and subsequent work of the group will be focussed on these areas.

How we will use the information

The information you provide can be completely anonymous. Whatever we learn from the surveys will be put into a report and passed on to the people who organise services and support so that we can influence and make sure that things are improved. It is important that you know that any comments you make will be anonymous in the report. We will also include positive feedback where good practice exists.

We will send a copy of the report to you if you complete your details below.

How you can take part

We would like to remain in contact with you, please complete the details below and send with the survey. If you want your answers to be anonymous please send the survey and your personal details back separately. Both can be returned to the same address.

If you would like to get feedback, information or be involved in a group or short term project please complete any relevant sections below as appropriate.



"Tell it as it is..."



A survey of the experience of people with Profound Intellectual & Multiple Disability
their family carers and supporters

Your Name:	
The Name of your family member or the person you support:	
Your relationship to the person you support or care for:	
Your Address:	
Telephone:	
Email:	
I would like a copy of the report	Please tick
I would like to find out more about being involved in a group about PIMD	Please tick
I would like more information about some of the issues raised in the survey:	Please tick relevant boxes below:
Specialised equipment	
Communication passports	
Person centred approaches	
Circles of support	
Health Action Plans	
Hospital Passports	
Individual budgets and Direct Payments	
Would you be interested in more information about other topics?	Please say what...

We really look forward to hearing from you. If you would like to ask us any questions about the survey or group please telephone Amanda Topps: 01524 586182 or email Amanda.Topps@lancashire.gov.uk.

Thank you very much for taking part.

Yours sincerely

David Grundy
Chair of the PIMD Group

Please return the PIMD survey **in the SAE** attached by **31st March 2012** or to **Amanda Topps** at The Knoll, Westbourne Road, Lancaster, LA1 5EF

About the person with profound intellectual and multiple disability (optional)

Name: _____

Gender:

Male Female

Age group:

14-18

18-25

25-65

65+

Which best describes the person's ethnic background?

A White

- English/Welsh/Scottish/Northern Irish/British
 - Irish
 - Gypsy or Irish Traveller
 - Any other White European background, write below
 - Any other White background, write below
-

B Mixed/multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/multiple ethnic background, write below

C Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Mixed/multiple ethnic background, write below

D Black/African/Caribbean/Black British

- African
- Caribbean
- Any other Black/African/Caribbean background, write below

E Other ethnic group

- Arab
- Any other ethnic group, write below

Which area do they live?

- | | | | |
|-----------|--------------------------|--------------------|--------------------------|
| Lancaster | <input type="checkbox"/> | Lytham St. Annes | <input type="checkbox"/> |
| Morecambe | <input type="checkbox"/> | Thornton Cleveleys | <input type="checkbox"/> |
| Garstang | <input type="checkbox"/> | Kirkham and Wesham | <input type="checkbox"/> |
| Carnforth | <input type="checkbox"/> | Fleetwood | <input type="checkbox"/> |

Rural area (please specify) _____

Other (please specify) _____

Which area does the person get social care or health services from? (Please tick all boxes that apply)

- | | | | |
|-----------|--------------------------|--------------------|--------------------------|
| Lancaster | <input type="checkbox"/> | Lytham St. Annes | <input type="checkbox"/> |
| Morecambe | <input type="checkbox"/> | Thornton Cleveleys | <input type="checkbox"/> |
| Garstang | <input type="checkbox"/> | Kirkham and Wesham | <input type="checkbox"/> |
| Fleetwood | <input type="checkbox"/> | | |

Rural area (please specify) _____

Other (please specify) _____

What is their living situation?

- | | | | | | |
|--------------------|--------------------------|---------------------|--------------------------|-----------------------|--------------------------|
| In the family home | <input type="checkbox"/> | In their own home | <input type="checkbox"/> | In a residential home | <input type="checkbox"/> |
| In a tenancy | <input type="checkbox"/> | In supported living | <input type="checkbox"/> | | |

Other (please specify) _____

If the individual gets social or health care funding, how does the person receive it?

Please tick all that apply:

- | | | | |
|---------------------------------|--------------------------|-----------------------|--------------------------|
| Managed by you | <input type="checkbox"/> | Self funded | <input type="checkbox"/> |
| Care managed by local authority | <input type="checkbox"/> | Direct payments | <input type="checkbox"/> |
| Care managed by an agency | <input type="checkbox"/> | Individual budget | <input type="checkbox"/> |
| Managed by a broker | <input type="checkbox"/> | Self directed Support | <input type="checkbox"/> |
| Continuing Health Care | <input type="checkbox"/> | No funding | <input type="checkbox"/> |
| A combination of the above | <input type="checkbox"/> | Don't know | <input type="checkbox"/> |

Other (please specify) _____

If you would like information about individual budgets or direct payments please get in touch.

About you (optional)

Are you are a family member or unpaid carer of the person who has PIMD? Yes No

Do you live with the person?

Yes No

If you would like please answer these questions:

Please give your name if you are happy to (otherwise it is fine to leave it out)

Gender?

Are you Male Female

What is your age group?

14-18

18-25

25-65

65+

Ethnic Origin? Which best describes your ethnic background?

A White

- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other White European background, write below
- Any other White background, write below

B Mixed/multiple ethnic groups

- White and Black Caribbean
 - White and Black African
 - White and Asian
 - Any other Mixed/multiple ethnic background, write below
-

C Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Mixed/multiple ethnic background, write below

D Black/African/Caribbean/Black British

- African
- Caribbean
- Any other Black/African/Caribbean background, write below

E Other ethnic group

- Arab
 - Any other ethnic group, write below
-

If you receive social care services for yourself which area do you get them from?

- | | | | |
|-----------|--------------------------|--------------------|--------------------------|
| Lancaster | <input type="checkbox"/> | Lytham St. Annes | <input type="checkbox"/> |
| Morecambe | <input type="checkbox"/> | Thornton Cleveleys | <input type="checkbox"/> |
| Garstang | <input type="checkbox"/> | Kirkham and Wesham | <input type="checkbox"/> |
| Carnforth | <input type="checkbox"/> | Fleetwood | <input type="checkbox"/> |

Rural area (please specify) _____

Other (please specify) _____

Are you a:

- Parent carer Family carer (sibling, grandparent, etc)
- Other Please specify _____

About you (optional)

If you are a paid carer or support worker working for an organisation, Shared Lives or self employed (for example, a personal assistant) please answer these questions:

Your Name:

Do you work for an agency or organisation? Please tick

Are you a Personal Assistant paid through a direct payment/individual budget? Please tick

If you are a personal assistant and would like to know about training opportunities please add your name and address or email:

We would really like to contact personal assistants who are supporting people with PIMD to identify where you get training from and if you have any additional training needs.

1. Terms of Reference from the PIMD Sub Group



North Lancashire Learning Disability Partnership Board

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



What our group is for and how it works

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



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:

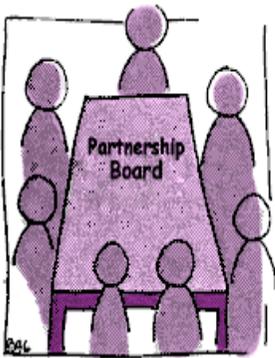
- have a profound learning disability and
- have more than one disability and



- 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 and their family carers, professionals from health, social care, education and children's services and organisations including providers of services across North Lancashire.

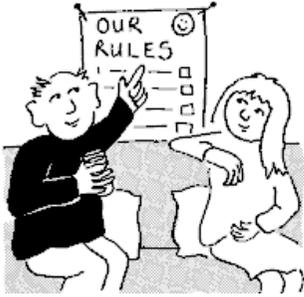
Group members from organisations will be expected to attend meetings or send a representative.

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.

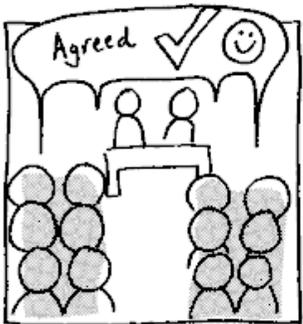
Any decisions made by the PIMD Sub Group will usually be reached on the basis of a simple majority view. In the event of a 'split decision' the Chairperson will have a casting vote.

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 group
- aim to improve the life experiences of people with PIMD through its work and action



- find out how many people with PIMD are in North 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 all the partnership board task and sub groups, the Lancashire Valuing People Now Board 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



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 Partnership Board 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

2.

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



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 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.

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.

3. Extract from People with Learning Disabilities in England Eric Emerson & Chris Hatton CeDR Research Report 2008:1 May 2008 pp2-5

How Many People with Learning Disabilities Are There in England?

It is not possible to estimate the number of number of people with learning disabilities in England either from information held by centrally government departments or from large-scale population based surveys. National statistical returns collected by government departments relate to specific services used by people with learning disabilities. For adults, for example, information is collected annually in the Referrals, Assessments and Packages of Care (RAP) from Councils with Social Service Responsibilities on people with learning disabilities using social care services. However, none of these data collections are comprehensive and none of these sets of data are linked. As such, it is not possible to estimate the number of number of adults with learning disabilities in England.

For children, however, information is collected on the special educational needs (SEN) of all children in maintained schools and non-maintained special schools. The latest information (from January 2006) indicates that, of these 8.2 million pupils, 171,740 (2.1%) had an identified primary SEN associated with moderate learning difficulty, 30,440 (0.4%) had an identified primary SEN associated with severe learning difficulty and 8,330 (0.1%) had an identified primary SEN associated with profound and multiple learning difficulty. In total, 210,510 (2.6%) pupils were identified as having a primary SEN associated with learning disabilities. This will, however, be a significant under-estimate of the actual prevalence for two reasons. First, data is only reported for children with either a Statement of SEN or at School Action Plus in the assessment of SEN. While data is collected on the nature of SEN for children at the School Action stage in the assessment of SEN, this data is not reported. This will have most impact on estimating the numbers of children with less severe learning disabilities. Second, data is only reported on the child's primary SEN. Although data is collected on secondary SEN, this data is not reported.

Given that it is not possible to estimate the number of number of people with learning disabilities in England either from information held by centrally government departments or from large-scale population based surveys, we were commissioned by the Department of Health in 2004 to derive robust estimates of current and future numbers of people with learning disabilities in England.

c In order to illustrate the potential significance of this omission we have analysed PLASC data from one Local Authority. In this locality, 6.4% of children with a primary SEN not directly associated with learning disabilities (e.g., behavioural, emotional & social difficulties, autistic spectrum disorder, sensory impairment, physical difficulties) were reported to have a secondary SEN associated with learning disabilities. Extrapolating this to national data would increase the estimated overall prevalence of learning disabilities to 236,000 (2.9%) pupils.

To do this we first extracted information from locally held learning disability 'registers' on the age and gender of 15,000 people with learning disabilities who are known to services in 24 Councils with Social Service Responsibilities covering a population base

of 3.2 million people (7% of the population of England). We then combined this with population data from the 2001 Census. We estimated that 177,000 adults (aged 18 or over, 0.47% of the total adult population) were known users of learning disability services in England. Of these, 26,000 were aged 60 or more.^d However, we know that many adults with (primarily mild) learning disabilities do not use specialist learning disability services.^{5 6} This may reflect a lack of 'need', a wish to avoid the stigmatisation associated with such services or that people are deemed 'ineligible' for social care services. As a result, we attempted to estimate the true numbers of people with learning disabilities in England. We estimated that 985,000 people in England have a learning disability (2% of the general population). This included 828,000 people aged 18 or more, of whom 174,000 were people aged 60 or more. It also included the 177,000 people aged 18 or more who were using services for people with learning difficulties.

In *Valuing People*, the Department of Health estimated that 65,000 children and 145,000 English adults have a severe or profound learning disabilities, and 1.2 million English adults have mild or moderate learning disabilities. While the basis for these estimates is not stated, it appears likely that they were derived by applying a standard prevalence rate unadjusted for age (2.5% for mild or moderate learning disabilities) to population predictions for 1999.

The Department of Health estimate for children (for which no age range is given) with severe or profound learning disabilities is 67% higher than DCFS data on the SEN of pupils. It is difficult to reconcile this apparent discrepancy as the DCFS figure is an underestimate (for the reasons pointed out above) and the Department of Health estimate for 'children and young people' includes pre-school children.

Given that the large majority of service users have severe or profound learning disabilities, the Department of Health estimate for adults with severe or profound learning disabilities (145,000) is consistent with our estimate of 177,000 known users of learning disability services. The discrepancy between the two is likely to be accounted for by our inclusion of service users with mild/moderate learning disabilities.

If we accept that 145,000 adults have severe or profound learning disabilities, then the Department of Health estimate for adults with mild/moderate learning disabilities is 84% higher than our estimate. This discrepancy is most probably due to the use by the department of Health of the same prevalence estimate (2.5%) across all age groups. In our estimates we used this prevalence estimate for the 15-24 age group but reduced estimates progressively with age to take into account the increased mortality of people with learning disabilities.

^d These figures have been updated for the present report to define adults as all people aged 18 or over.

Are the Numbers of People with Learning Disabilities Changing?

Given that no accurate records are kept of the number of people with learning disabilities in England, it is not possible to determine whether these numbers are changing. A number of factors could lead to a change in the number of people with learning disabilities in England. These include both factors that will influence the future size and composition of the English population (e.g., changes in overall birth rates, migration and mortality), and possible changes in the incidence and prevalence of learning disabilities.

General Demographic Change

Population predictions for England are provided by the Government Actuary's Department (<http://www.gad.gov.uk>). Current predictions suggest that English population will rise from 50.9 million in 2007 to 53.5 million in 2017 and 56.0 million in 2027. However, these overall changes conceal marked changes in the age-structure of the population. The number of young people aged 0-19 is expected to drop from 12.3 million in 2007 to 11.9 million in 2017 (-3%) and then recover to 12.2 million in 2027 (0% change from 2007). The number of adults aged 20-64 is expected to rise from 30.5 million in 2007 to 31.6 million in 2017 (+4%) and 32.0 million in 2027 (+5% change from 2007). The number of older adults aged 65+ is expected to rise from 8.2 million in 2007 to 10.0 million in 2017 (+22%) and 11.8 million in 2027 (+45% change from 2007).

If we assume that there will be no changes in the incidence and prevalence of learning disabilities, these changes in the general population will result in equivalent changes in the population of people with learning disabilities.

Potential Changes in the Incidence and Prevalence of Learning Disabilities

The incidence and prevalence of learning disabilities will be influenced by a range of factors including changes in: rates of exposure to environmental hazards that may cause learning disabilities (e.g., infections, toxins, road traffic accidents, poverty and social deprivation); access to and uptake of screening and selective termination; the life expectancy of people with learning disabilities; access to and uptake of interventions that may prevent learning disabilities (e.g., phenylalanine free diet, early intervention, potential gene therapies).

In our work for the Department of Health, we argued that three factors are likely to lead to an increase in the age-specific prevalence rates for adults with learning disabilities in England over the next two decades.

These are: (1) an increase in proportion of younger English adults who belong to Bangladeshi and Pakistani South Asian minority ethnic communities (among whom evidence suggests there may be a two to three fold increase in the prevalence of more severe learning disability in children and young adults); (2) increased survival rates among young people with severe and complex disabilities; (3) reduced mortality among older adults with learning disabilities.

By modelling the effects of these changes and combining these with the effects of general demographic change we estimated modest but sustained growth over the next two decades in both the numbers of people with learning disabilities known to learning disability services (11% over the decade 2001-2011, 14% over the two decades 2001-2021) and the estimated 'true' number of people with learning disabilities in England (15% over the decade 2001-2011, 20% over the two decades 2001-2021).^e These projections were used by the Department of Health to justify the need to review the organisation of social care in England¹⁰ and are broadly consistent with the predictions made in *Valuing People*.⁷

Within the 15-49 age range we predicted very little change in either the number of people with learning disabilities known to learning disability services (4% over the decade 2001-2011, only 0.2% over the two decades 2001-2021) or the estimated 'true' number of people with learning disabilities in England. However, within the 50+ age range we predict very marked increases in both the numbers of people with learning disabilities known to learning disability services (28% over the decade 2001-2011, 48%

over the two decades 2001-2021) and in the estimated 'true' number of people with learning disabilities in England (31% over the decade 2001-2011, 53% over the two decades 2001-2021).

Increased demand in the older age groups is of particular significance since older adults with learning disabilities are significantly more likely than younger adults to rely on public funding for supported accommodation. Indeed, we predicted that (assuming the level of rationing of residential support remains constant) public agencies in England will need to provide out-of-home residential support for an additional 12,000 older adults with learning disabilities by 2011 and for an additional 20,000 by 2021.

^e The predicted slowing down in the growth of the population of people with learning difficulties reflects the impact of decreased child population in the period up to 2017 and the ageing of the general population

4. Extract from Lancashire Multi-Agency Carers Strategy 2013-15 pp1-12

Over the summer of 2010, the Department of Health sought views on what the priorities over the next four-year period should be. Over 750 responses were received, representing the views of over 4,000 carers. The Department of Health also asked the Standing Commission on Carers, the Government's expert advisory group for its views on priorities.

Key messages from the responses were:

- Carers need better and timely access to information – on the illness or condition of the person they are caring for; on appropriate caring; on accessing benefits and other support; and on financial and employment issues;
- Carers can often feel excluded by clinicians – both health and social care professionals should respect, inform and involve carers more as expert partners in care
- Carers find accessing assessments overly bureaucratic and slow, and are often disappointed about the paucity of the services that follow
- Carers often feel forced to give up work to care
- Carers often neglect their own health and need advice to maintain their wellbeing
- Carers need breaks from caring in order to sustain their role as a carer
- Carers feel that the value of Carer's Allowance is inadequate, the rules around overlapping benefits are unfair and the earnings limit is a disincentive to work

Commissioning implications...

We need to ensure that carers have the information they need at the right time for them.

We need to ensure that health professionals receive carer awareness training to enable them to recognise a carer, value their opinion as an 'expert' and to be able to signpost carers to services which can help them.

We need to ensure that carers have the opportunity of having a good quality, timely carer's assessment, which addresses their needs.

We need to ensure carers, should they choose to, are supported to maintain their employment.

We need to identify ways to support carers to maintain their health and wellbeing.

We need to ensure there is a range of options for carers to enable them to take a break.

We need to ensure carers are treated as expert partners in care.

5. Carer's Allowance

Carer's Allowance is a non-contributory benefit paid at a standard rate per week. (In 2010-11 this was £53.90 per week.) The scheme was introduced (as the Invalid Care Allowance (ICA)) in 1975. Coverage was extended to married women in 1986, and to over 65s in 2002.

The main conditions of entitlements are:

- the claimant is providing informal (i.e. unpaid) care to an elderly or disabled person, for at least 35 hours per week;
- the disabled person is receiving AA, or the middle or higher rate of the care component of DLA;
- the claimant is earning less than £100 per week, net of tax and other deductions, and is not in full-time education;
- only one carer can claim for helping any disabled person; and a carer can claim for helping only one disabled person.

If the claimant fulfils these four main conditions (and also is 'resident' in Britain), s/he will be 'entitled' to Carer's Allowance. But s/he will not actually be paid any allowance, if s/he is also receiving 'overlapping' earnings-replacement benefits (mainly the State Pension, Jobseeker's Allowance (JSA) or the Employment and Support Allowance. In that case, s/he will be treated as having an 'underlying entitlement'.

People entitled to Carer's Allowance (whether receiving a payment or not) are also entitled to the carer premium in Income Support (IS), Housing Benefit (HB) or Council Tax Benefit (CTB), or the carer's addition to Pension Credit (PC), worth up to £30.05 per week (rates for 2010-11). But people with underlying entitlement whose family income exceeds the various means-test thresholds will gain no increase in weekly income. If the disabled person lives alone and receives the severe disability premium for means-tested benefits, the carer cannot receive CA. And vice versa. One of these entitlements can be claimed, but not both.

6. Conclusions and recommendations from the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities, 2013

Chapter summary

The key recommendations from the CIPOLD review of deaths are:

- 1 Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.
- 2 Reasonable adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.
- 3 NICE Guidelines to take into account multi-morbidity.
- 4 A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
- 5 Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.
- 6 Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.
- 7 People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
- 8 Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.
- 9 Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
- 10 Mental Capacity Act advice to be easily available 24 hours a day.
- 11 The definition of Serious Medical Treatment and what this means in practice to be clarified.
- 12 Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
- 13 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England.
- 14 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.
- 15 All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.
- 16 Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.
- 17 Systems to be put in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments.
- 18 A National Learning Disability Mortality Review Body to be established.

7. Your Community

How are people spending their time?

Places people go

Adapted cycle schemes
Art Class
The bank
Blackpool
Botany Bay
Bowling
Building Society
Cafés
Car rides
Chip Shop
Church
Cinema
Cinema Club
College
Countryside
Cycling
Day Services
Disco
Doctors
Drama
Drive in the car
Entertainment
Fish pedicure
Garden Centre
Hairdressers
Holidays
Horse riding
Hydrotherapy
Kendal
Lancaster
Lancaster/Morecambe/Lake District/Yorkshire Dales/Peak District
Leighton Moss RSPB
Leisure Centre
Library
Liverpool Albert Dock
Manchester Airport (by train)
Mencap Club
Morecambe
Multi Sports
Music Class
Music therapy
Out in the wheelchair
Parks

Poulton
Preston
Pubs
REDS Dining Society
Respite
Restaurants
Ride in the car
Sensory drama
Shopping
SPACE Preston
St Annes
Supermarkets
Swimming
The Holistic Centre at Overton
Theatres
Trafford Centre
Trains
Trampolining
Travelling by bus
Trips out
Visiting friends
Walking including being a member of a walking group
Windermere
Zoo or Animal Park

8. Housing

Excerpt from the **HOUSING ACTION PLAN 2012 – 2017 Lancaster City Council** November 2012 pp41-44.

People

Meeting the housing needs of all parts of the community

4.1 The Council, as both an enabler and provider, plays a fundamental role in meeting the needs of vulnerable people that live within our community. The term “vulnerable” or “socially excluded” describes groups that are likely to have additional housing needs and will experience poorer outcomes if these needs are not met. These groups include:-

- People with physical and/or learning impairment/disability or mental ill health
- Homeless households
- Young people
- People suffering domestic abuse
- People with a history of substance misuse/dependency
- People with a history of offending behaviour
- People from BME/Gypsy and Traveller communities
- Older People

4.2 The Housing Needs Survey 2011 showed that 23% of people living within the District have a disability or support need, which is higher than the national average. Meeting the needs of vulnerable people is very often two-fold. It is concerned with providing suitable housing, and providing the appropriate support needed for people to meet their needs and aspirations.

People with Learning Disabilities and/or Physical Disabilities

4.9. The services provided for those with learning disabilities are currently fully integrated with adult services, and are funded and commissioned through separate governance arrangements within the SP programme. Often, people with learning disabilities also have physical disabilities and require very specialist accommodation and care. Both Lancashire County Council and the City Council will need to take account of the aspirations of those with learning disabilities in how future services are modelled. In particular, some service users have a desire to move away from group settings and live independently and there will be a greater reliance upon assistive technology to enable service users to do this. It is critical that Lancashire County Council works closely with the

Council to ensure that the future needs of this group are carefully mapped and identified so that there is sufficient provision of suitable accommodation for this purpose. Focus groups across the three localities of the County are planned to look at this in more detail, and any proposed new developments will require endorsement from Housing Benefit Managers, with new housing being provided by Registered Providers under normal circumstances.

4.10 Meeting the needs of those with physical disabilities and/or sensory impairment can often be complex, depending upon the requirements of the individual, their care needs and the household composition.

4.11 The vast majority of the local authority's housing stock was not built or intended to meet the varying needs of wheelchair users. However, the Council is fortunate in having a dedicated budget set aside for adaptations to Council dwellings. Large scale alterations can be costly and do not always provide a long term solution in some cases. This is why it is so important that new housing is provided to lifetime homes standards, which are easily adaptable to meet changing needs. There are well established links with the Community Occupational Therapy Teams who provide detailed information about the needs and requirements of households where a member of the family has a disability, and joint assessments can be undertaken to check the suitability of any housing being offered.

4.12 Through the planning process, and during negotiations for affordable housing, the Council will seek to secure some provision of wheelchair properties as part of the on-site affordable housing on a site by site basis. Furthermore, any sites which are wholly affordable rented housing will normally include some wheelchair provision where possible.

4.13 There are a small number of purpose built wheelchair units across the existing social housing stock, which is generally level access flats or bungalow accommodation, as well as wheelchair properties within some of the sheltered housing schemes. A handful of properties have through floor lifts installed, generally where the family composition is too large for their needs to be met in level access accommodation. All social housing providers should make the best use of these properties when vacant and endeavour to allocate properties to those households who needs best match. A potential area for development would be to consider compiling a register of adapted social housing, which is recognised good practice, to ensure the most appropriate matching of suitable applicants through the Council's Choice Based Lettings Scheme, with agreement that all adapted properties are advertised through the CBL with appropriate labelling of property attributes.

9. The PIMD Group discussed questions at their meetings to take to the Specialist Mobility Rehabilitation Centre in Preston on 3 October 2013.

Members of the group visited Phil Purcell, Quality Manager at the Specialist Mobility Rehabilitation Centre in Preston.

These were the questions we asked, the answers we received are in **bold**.

We were told that the service covers south Preston to north Barrow, Fylde and Yorkshire. They have 23,000 customers. When people are referred they are assessed within 12 weeks and issued with a chair. The number of referrals they have received has gone up from 500 to 850 per month. They issue 750 units per month. They have key suppliers and negotiate discount on volume. The contractor provides the spares.

- What services do you provide at weekends and out of hours for repairs?
Services are available 365 days of the year. The weekday service is open 8.30am-5pm. The out of hours service is available 5-11pm, weekends and bank holidays. The out of hours number is on the website and there is a label on chairs they issue with the out of hours telephone number on. All the contact details are in the user handbook. User handbooks are given out with all new chairs.

- What is your policy for time scale regarding repair and call out? (Flagging System)

A family carer gave the example: They were told there were no spaces for 3 working days then someone will ring up and put you on a list.

Another example given was that the service came out with no replacement parts. Eg. a family were waiting for six weeks for a motor. They do not bring a replacement chair for the person to use while they fix the broken chair.

Eg. one family member reported the current provider using 'no nails' to fix the back of the wheelchair on.

They have 3 days to complete the repair. If the person uses a powered chair they will provide a spare manual chair, while the chair is repaired. They have 8 repair vans and work is planned. In an emergency they will provide a same day or next day service. They need to know the requirement of the person to be able to re-prioritise their list. The repair time is part of the key performance indicators for the repair contract. If the person states when ringing that they 'cannot function without their chair' this helps the customer care centre know to prioritise the repair.

Group members wanted to note that children have a good service in schools.

- Why do people buying a private chair with voucher then have to pay for repairs and maintenance?

The wheelchair is classed as theirs so they have to pay for maintenance. Any chair procured through the SMRC is maintained by the repair contract. They issue 500 vouchers per year. They are worth £305, £410, £700 and £1,400. Vouchers mainly are used for aesthetic reasons, eg wheelchair colour. Vouchers are not issued for powered chairs.

The produce range is much broader now and procurement is different. Wheelchairs can have complex seating, modular, low volume, moulded and be customised. The decision is based on clinical assessment. OT will get information about weight, height, etc then will select equipment.

- What is the policy for reviewing the wheelchair?

There is no automated reassessment. You need to self refer for re-assessment.

Information about this is in the Handbook which is given out with a new wheelchair.

For specialist seating the OT team have a cyclical system in place. The GP can trigger a referral to the consultant who triggers activities within specialist services.

The current service contract triggers a review every 2 years. Each piece of equipment has a unique asset number and is given a full MOT every 2 years. The contractor will refer back for clinical review if issues are identified or they see changes at this review.

The contract engineers are all CRB checked and are NVQ trained and have disability awareness training.

- What is the policy assessing for carers needs for using wheelchairs?

Eg. carer asked for a powered chair due to their own health needs but were given a manual chair.

Services do consider the carer when prescribing, eg lighter equipment. Powered wheelchairs are prescribed if the patient is both unable to self propel and unable to walk. They get a letter of clinical support from their clinician. Services are aware that there is an ageing population of carers. 350 powered wheelchairs are issued per year. There is a 3 year waiting list for powered chairs. Commissioners are aware of this. Power packs for manual chairs are not funded. They cost £700-1000 each.

- What is your business plan for improvement for next 12 months?

- What is your policy and time frame for complaints?

They follow the ISO 9001 system regarding complaints procedures. They do an annual patient feedback survey. Not all patients are surveyed but a selection. There is also a Quality Forum which Phil chairs. We were invited to send a representative. All services are represented not just wheelchair services. They said they tend to get more compliments than complaints. Phil also attends a national Wheelchair Managers Forum.

- We are not aware of a feedback system being in place. What is the complaint and compliments system?

When a concern is raised verbally it is logged on the system and passed to Phil Purcell. They class this as an informal complaint and have 20 working days to respond. If the complaint is written it is classed as a formal complaint, Phil investigates it and is taken through the Trust complaints procedure via Lancashire Teaching Hospitals and the outcome goes to the Chief Executive of the Trust, Karen Partington. Look on the Lancashire Teaching Hospitals Website for details of how to complain and look for the Specialist Mobility Rehabilitation Centre.

- Is there any procedure in place for prioritising people with PIMD or any other related disability?

They cannot prioritise individuals other than people on hospital discharge, people near the end of life or military veterans or if there is a safety issue. To lobby for change they recommended contacting our MPs and for the Partnership Board to lobby. The Specialist Services Commissioning Team currently buy services on behalf of 5 CCGs.

10. Lancashire Communication Checklist

Checklist of communication strategies

Strategy		Comments
Are you aware of total communication?	Y/N	
Does each service user have a communication passport/ guide?	Y/N	
Have any staff had any training in:		Give details– what, who from, number of staff etc.
<ul style="list-style-type: none"> Communicating with people with learning disabilities 	Y/N	
<ul style="list-style-type: none"> Total communication 	Y/N	
<ul style="list-style-type: none"> Intensive Interaction 	Y/N	
<ul style="list-style-type: none"> Signing 	Y/N	
<ul style="list-style-type: none"> Talking mats 	Y/N	
<ul style="list-style-type: none"> Social stories 	Y/N	
Do the service users access choices through visual supports e.g.:		
<ul style="list-style-type: none"> Written word 	Y/N	
<ul style="list-style-type: none"> Symbols 	Y/N	
<ul style="list-style-type: none"> Photos 	Y/N	
<ul style="list-style-type: none"> Objects of reference 	Y/N	
Does every service user have a personally adapted copy of their activity timetable?	Y/N	
Do you use visuals to display:		
<ul style="list-style-type: none"> Staffing rota 	Y/N	
<ul style="list-style-type: none"> Timetables 	Y/N	
<ul style="list-style-type: none"> Step-by-step instructions e.g. personal hygiene, making cup of tea 	Y/N	
<ul style="list-style-type: none"> Personal shopping list 	Y/N	
Do you use:		
<ul style="list-style-type: none"> Sign of the week 	Y/N	
<ul style="list-style-type: none"> Are they displaying the current sign? 	Y/N	
Have you produced/ use accessible information:		
<ul style="list-style-type: none"> Consent forms for the service user 	Y/N	
<ul style="list-style-type: none"> Leaflets, policies, procedures etc around communication 	Y/N	
<ul style="list-style-type: none"> Is it using simplified language and pictures? 	Y/N	
Do you currently use:		
<ul style="list-style-type: none"> Communication aids 	Y/N	
<ul style="list-style-type: none"> Talking mats 	Y/N	
<ul style="list-style-type: none"> Social stories 	Y/N	
<ul style="list-style-type: none"> Intensive interaction approach? 	Y/N	
Any further comments, including any examples of creative use of communication strategies		

Checklist for communication strategies How and why to use it

What is the checklist:

The checklist is a qualitative measure used to look at the service providers' use of communication strategies. This is done through analysing the service provider's awareness of communication strategies and ability to access and/or use communication strategies to support the individual.

Each service provider within Lancashire will be given a checklist in order to raise their awareness of a variety of communication strategies and to give them the opportunity to demonstrate the strategies that they are currently using.

Providers can use the checklist to:

- Demonstrate a person-centred approach
- Inform a Physical intervention quality check regarding the communication strategies used
- Promote their service to new service users
- Demonstrate to social workers the communication strategies in place

Why was the checklist developed:

The use of communication strategies are essential so that each individual is enabled to:

- make informed choices and have control over the options available to them
- express their opinion and have maximum participation in best interest decisions
- understand messages communicated to them and be able to communicate their desired message
- access activities and develop daily life skills

There has been a need identified as people can be placed within services who are unable to support an individual's level of communication need.

The checklist works through a variety of communication strategies that would give a staff team a gold standard of communication care to work towards. The checklist will raise awareness of the types of communication strategies that are available and will help services to know how they can support individuals appropriately.

The level of communication strategies required for the individual will differ. **The provider is not being judged for not using communication strategies that are not relevant to the individual.** The following table shows what communication systems are likely to be needed within the diagnosed severities of learning disabilities.

Level of learning disability	Anticipated communication strategies
Mild	Simplified language. Communication passport. Use of accessible information. Possible use of social stories.
Moderate	All above plus visual supports, talking mats, and possible use of signing or communication aid as support.
Severe	All above plus objects of reference, full use of visual supports, intensive interaction, signing communication guide.
Profound	Total communication, Communication guide, Intensive interaction, objects of reference.

How to use the checklist:

It is simple to use. Go through the checklist circling yes/no for each area providing comments where appropriate. The more yes's that are recorded the closer the service provider is likely to come to a gold standard of communication care. Considering the individual's level of need the checklist will identify if the service is currently able to meet the needs of the individual.

For further information about the detailed communication strategies please see the attached glossary of terms, alternatively see the Communication task groups website www.clpb.org and follow links to task group and communication or the oxford total communication website www.oxtc.co.uk.

Glossary of terms

Total Communication:

Total communication is an approach that encourages the use of all modalities of communication i.e. not just speech. For example total communication can utilise body language, facial expressions, photos, symbols, signs, touch and intensive interaction. Total communication aims to ensure that each individual is communicated with and is provided with the means to communicate in the most accessible way for them.

Communication passport/guide:

A communication passport gives a brief outline of how the individual communicates and the best way to communicate with them. It also looks at the individuals likes and dislikes. A communication guide also encompasses this information but it is produced to be highly visual and motivating, it also encompasses practical communication strategies e.g. a choice board, visual timetable or visual support for shopping. The guide should be kept on the individual at all times and be used to encourage communication and track communication breakthroughs. For more information see www.csrpcp.net follow the person centred planning tools and communication tools links.

Intensive Interaction:

Intensive Interaction is a form of communication where the communication partner interacts at a level that suits the individual. This is often used with individuals with severe learning disabilities and/or autism. Is it used to teach the pre-speech fundamentals of communication e.g. turn taking, eye contact, facial expressions. It teaches individuals that they can have an effect on others and the world around them.

Signing:

Signing provides a visual support to enhance speech, it also helps to gain and focus attention on the communicated message. Within learning disabilities the signing systems most commonly used are Signalong or Makaton.

Talking Mats:

Talking mats use visual supports to aid conversations, to allow a person to make decisions and to look in depth into an individual's opinion. Talking mats allow an individual to state if they like, don't like or are unsure about a specific topic. Any topic can be explored and this can be done spontaneously using hand drawn pictures or written words if appropriate.

Social Stories:

Social stories are short stories that use simple language and generally use pictures to improve an individual's understanding of a situation. They aim to prepare an individual for new situations and help an individual to respond appropriately to situations. Social stories allow the individual time to process the information about a situation and can be revisited.

Objects of reference:

This can be a formalised system where the same object is used to represent an activity or message or where by a staff member uses an object impromptu e.g. giving the individual a coat to let them know they will be going out, or swimming shorts to tell them they are going swimming. Objects of reference are then learnt so that the individual can then use the object to choose to do an activity. This can be particularly useful for individuals with severe/ profound learning disabilities, visual impairment or individuals with dementia.

Visual aids:

Photographs, pictures and symbols (written in increasing order of difficulty to understand) can be used to reinforce a verbal message or as the main form of communication. Individuals could be shown visuals to let them know what activity they will be doing or what to expect later. Schedules can also be created to provide an individual with a simple to understand step-by-step instruction manual to complete an activity as independently as possible. Staff photos can be used to show who is on shift later. Visuals can be used to enable an individual to make choices.

Communication aid:

A communication aid is used to help the individual understand a message given to them or provides them with the means to communicate. This is a system which generally uses photographs or symbols but can use words. This can be either a high tech device or a low tech device. A high tech device might look like a small hand held computer and might have a voice output, it could also be an iPad. A low tech device might be a few pictures kept in a book or on a key ring.

An individual should have access to their communication aid at all times.

11. Communication Passports Leaflet



Communication Passports



What are they?

A communication passport explains how an individual communicates, for example, how they show they are happy, they don't like something or they are in pain. These are crucial documents to help form decisions around whether the person can consent to a particular decision.

What do they look like?



A passport can take a variety of different forms; small booklets produced on a computer, scrapbooks with pictures stuck in, 'Talking Photo Albums' (with programmable sound bytes), CD-roms and even apps for tablets! It doesn't matter which method is used, as long as it captures the information about that person's communication that is needed to form a relationship.

What do we do with them?



The passport belongs to the person. They are living documents—people change and the passport will change too to reflect this. Communication develops over time and the passport will help structure this and capture progress.

The communication passport has been useful at college with the tutors not knowing the person

Who is it for?



Communication passports are particularly helpful for people who have difficulty communicating in a conventional way and may have developed a number of ways to express meanings that are personal to them.

Who can put it together?



The passport is put together with the person by anyone who knows the person well such as family members or paid carers. Training sessions are delivered throughout the year in North Lancashire. Support can also be accessed from the local Speech and Language Therapy service, see over for details.

How to make a basic communication passport

A good place to start is to use a Communication Table to capture how the person expresses meanings;

In this situation	When I do this	It probably means	And you should
E.g. At the end of the day	Look towards my hoist	I would like to go to bed	Ask me if that's what I mean and I will say 'yeah' if you are right

All you need to do is list the ways that the person expresses themselves which may not be picked up by someone who does not know the person so well.

Then ask other people who know the person well to contribute, involving the person themselves as much as possible to check things out with.

This table will then go into the "How I express myself" section. You may want to think about including information about how the person communicates 'yes' and 'no', how the person expresses pleasure / displeasure.

Other useful sections to include in a communication passport are:

- Cover page with a photo of the person
- Contents page
- Important information page—this will include things which are very important to know when supporting the person which they may not be able to tell you.
- How I express myself
- How I understand you
- How I make choices

Has helped new staff recognise how he communicated

When you have some content in draft form, decide with the person how you want it to look, think about colour schemes, font, use of photos, size, laminating pages, binding, having a digital copy, etc.

Useful contacts / links	Lancashire Care  NHS Foundation Trust
Lancashire Care NHS Foundation Trust: Adult Community Learning Disability Service	
Speech and Language Therapy service	
• Lancaster and Morecambe district: 01524 550330	
• Fylde and Wyre district: 01253 956179	
Useful websites:	www.northlancsleads.net
	www.communicationpassports.org.uk
	www.oxtc.co.uk/resources.shtml



The Lancashire Learning Disability Partnership Board

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