

## CONSULTATION QUESTIONS

### Progress and Challenges

**Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?**

Yes  No

Please provide comments, evidence/or examples here:

The process *PAMIS* used to collate our response to the consultation involved: two senior members of staff taking the initial responsibility to read all relevant documents, e.g., the SCLD led Evaluation Findings; the Scottish Government's consultation form; draft responses from other LD organisations as relevant; held focus groups of *PAMIS* family carers – one in Glasgow and one in South Lanarkshire to collate family carers' views; consult with other *PAMIS* staff; draft the response; this was then commented and revised by three other members of staff - the Director, Information Officer and Senior Family Support Service Co-ordinator - who finalised *PAMIS*' response to this consultation.

#### **Evaluation Findings:**

In general terms, *PAMIS* agrees that the evaluation findings to date (some not yet available, e.g., the SAY Health Inequalities and Learning Disabilities Consultation Conference) broadly reflect our views. In a wide ranging evaluation such as this we recognise it is not possible to reflect fully the needs of all people with a learning disability and we are particularly focused on the needs of people with profound and multiple learning disability (PMLD) who also have complex healthcare needs and their parents/carers. Our responses to the questions throughout the consultation form will concentrate on the very specific needs of this group of people and where relevant comment more broadly.

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**Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?***

**Closure of Long-stay Hospitals:** The long overdue closure of long stay hospitals has been very positive.

**Community presence:** People with a learning disability have become more visible in their communities and there are many examples of where they have been involved in service design, strategic planning, peer support and peer training.

**Engagement in consultations, policies and practice:** Engagement and consultation with services users and carers and the voluntary sector in aspects of design and development of new services has improved. Involving patients, carers and the public is an important part of improving the quality of services provided by NHS Scotland and Social Work. The development of local policy and practise has improved for carers as a result

of public engagement policy for example: NHS Quality Improvement Scotland, Healthcare Services for People with Learning Disabilities<sup>1</sup> included carers and service users as part of the review teams. Carers are often part of strategic planning groups through the government, NHS and local authority.

**Examples:** A local example of carer involvement in improving care in the acute hospital setting is NHS Tayside Complex Care Reference Group. This group is fully involved in the implementation of NHS Tayside's Learning Disabilities Improvement Plan, the development of their e-learning foundation course for all hospital staff and the training of medical students. This innovative multi-professional 4 week self-selected component enables students to explore how their clinical skills can be used to their maximum effectiveness.

Another example of improved consultation with families is Perth and Kinross. The Social Work Department organised and delivered an excellent consultation process during the redesign of day service provision and their three year strategic plan 2012 – 2015.

A national example of user and carer involvement in strategic planning and implementation is service users, family carers and representatives from PAMIS in the Scottish Government's SAY National Implementation Group and its Users & Carers sub-group. More recently, the involvement of the voluntary sector in the implementation of the SDS National Strategy is commendable.

1. NHS QIS (2009) *Tackling Indifference: Healthcare Services for People with Learning Disabilities - National Overview Report*. Edinburgh: NHS QIS

**Legislation and policies:** Over the past 10 years a number of new Acts of Parliament and national policies have been introduced that impact positively on the lives of people with PMLD and their family carers: these include: The Adults with Incapacity (Scotland) Act 2000 – the inclusion of Welfare and Financial Guardianships in this Act is very much welcomed and used by family carers; The Adult Support and Protection (Scotland) Act 2007 and the Social Care (Self-Directed Support) (Scotland) Bill 2012, are also very good examples of empowering legislation. National policies that have effective change include: the personalisation agenda; person-centred planning; and annual health checks (though these are not Scotland-wide) are also welcomed. The introduction of Learning Disability Nurse Consultants and Liaison Nurses are viewed - where they are in post - as extremely necessary, cost effective and contribute to improved health care and quality of all people with learning disabilities and particularly those with profound and complex healthcare needs.

### Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?

Please provide any comments and/or examples here

**Early intervention:** The benefits of early intervention for children with disabilities and particularly those with profound and multiple learning disabilities are well documented<sup>1,2,3</sup>. Whilst there are some examples of good practice in place throughout Scotland we still have a long way to go for this to be a reality for all young children with PMLD. Examples of good practice of early intervention policies and practice are; TAC Interconnections' Team around the Child initiatives, developed by Peter Limbrick - see <http://www.teamaroundthechild.com/> and Scotland's Getting it right for every child (GIRFEC) approaches. In the local authorities where these are in place they viewed as being highly beneficial but there is a need for these to be implemented fully throughout Scotland.

There are a number of voluntary organisations that can offer support to families caring for a child with complex disabilities in the early years, however, it is very difficult to get information on such organisations to the families, due to the 'gate keeping' practices used by many pre-school services, particularly those that run by or involve paediatric medical professionals. Once the families gain access to such support they have on many occasions, expressed their disquiet about the lack of transfer of information of such sources of help and support. We need more open and transparent referral systems and parents being given the opportunity to take the decision whether or not to access these sources of help.

<sup>1</sup>*Removing Barriers to Achievement: The Government's Strategy for Special Educational Needs.* (2004). Department for Education.

<sup>2</sup>*The Early Years Framework.* (2008). Scottish Government: Edinburgh.

<sup>3</sup>Dixon, J. (2006). Future Focus: Early Years. *PMLD Link*, 8(1), 3.

**Transition from child to adult services:** This is a time of great stress and anxiety for both the person with PMLD and the whole family. All children with in Scotland, whatever the degree of their disabilities have an absolute right to an education. Their education and health care needs are appropriately met while there are in the education system. During the child's school years, the parent can and often do take up part-time employment or voluntary work, which give them opportunities to become involved in their local community. However, once their daughter/son moves to adult services there is no guarantee of a 5-day a week, structured day service, with one-to-one support, where their social, health and intimate and personal care needs are met. This is what family carers need and want – and this was recognised in SAY? 2000. Additionally, the opportunities on offer should include activities that not only maintain but extend the skills and abilities the person learned and developed during their school years. The implementation of SDS policies (and how they are being introduced is markedly different across Scotland), coupled with the loss of benefits such as the Independent Living Fund (ILF), and the many cuts to packages of care, will result in increased family stress, and in many cases breakdown of the family unit. All this will result in parents being no longer able to cope, the young person having to move into an unplanned residential setting and the whole care package costing much more than would if correct day

service options were in place. What is needed is the recognition of the needs of this group of vulnerable people once they reach adulthood. They should be provided with a properly funded package of care that is based on assessed need and not governed by budget costs alone. Many care packages on offer at present force the parent/carers to choose between a full day-service with little or no respite or a much reduced day service and some respite. Clearly this is neither appropriate nor fair.

**Respite and short-breaks:** Residential respite services, there is a real shortage of appropriate residential respite services that meet the specific needs of people with PMLD. That is, services that are physically accessible, with staff trained and competent to deliver procedures such as non-oral feeding, deep suctioning, moving and handling, and non verbal communication. *Short-breaks:* there is still a need for more and innovative short breaks for people with PMLD, with the required ratio of staff, staff that are trained in the procedures noted above. The Scottish Government has recently made available considerable funding for such short breaks, however, people with PMLD have not benefitted as well as PAMIS had hoped from this funding source.

**Further and continuing education:** Historically people with learning disabilities in general and those with profound and multiple learning disabilities in particular, have been denied the right to access Further and Continuing Education. We have in the recent past made some progress with opening up this source of learning but as the recent SCLD and its partners Project Antenna demonstrated in its report<sup>1</sup>, there have been many cuts to college places for students with learning disabilities.

<sup>1</sup>SCLD (2011) *"If I don't get a place next year, I don't know what I'll do"*: Joint SCLD Briefing on the impact of changes to the funding of students with learning disabilities within Scottish Further Education. SCLD; Glasgow

There is an urgent need for colleges and their courses to be become both physically and intellectually accessible to students with PMLD. Courses must also be meaningful learning based, as defined by Scotland's Profound and Complex Needs project team. This project has made great strides in really listening to family carers and professionals supporting them and in ensuring they now offer courses that are accessible to people with PMLD. However, the funding for this highly important work has recently come to an end. PAMIS would like to see the excellent work of the project team to not only continue but expand.

### **Good Practice – Organisations**

**Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?**

As an organisation PAMIS has been active in both national and local policy planning and development of initiatives that improve services and access to services. Through The Family Support Service, campaigning, provision of

training workshop, advice and information, responding to consultation both nationally and locally and through the specialist service *PAMIS* provides to individuals with PMLD and their family carers, the organisation has helped improve services and access to services for this group of people considerably over the last ten years.

### **Family Support Service**

In the individual areas where *PAMIS* works, family support service co-ordinators provide practical information, advice and one-to-one ongoing support to families with sons or daughters with PMLD. This model of support ensures that the families are supported to negotiate for services that are appropriate to the needs of their sons and daughters.

### **Training workshops**

*PAMIS* provides regular training workshops for family carers on a wide range of topics, for example: moving and handling, managing epilepsy, Self Directed Support. These training workshops are designed to keep family carers informed of changes in government legislation, policy and practise, for example Adults with Incapacity (Scotland) Act 2005, Adult Support and Protection (Scotland) Act 2007, Social Care (Self-Directed Support) (Scotland) Bill, 2012. Other training workshops are designed to address the complex health care needs of people with PMLD for example Recognising the emotional and mental well-being of people with PMLD. Participation in these training workshops ensures the family carers are fully informed and better able to contribute to local consultations that are relevant to service provision.

1. Philip, M., Lambe, L., Hogg, J., & Alcoe, J. (2005). *The Well-being Workshop: Recognising the emotional and mental well-being of people with profound and multiple learning disabilities - A training resource for family carers and support staff*. London:

### **Accessible leisure activities**

*PAMIS* provides and promotes accessible leisure activities and offers practical advice for inclusion in community activities. This ensures improved health and well-being people with PMLD and their family carers.

For example; Sporting Opportunities for Motor Activities (SOMA), wheelchair ice-skating, adapted bikes, horse riding, carriage driving and rebound.

Introduction and promotion of these accessible leisure activities by the Family Support Service through the strategic planning groups ensures these opportunities are embedded in local planning policies.

### **Research**

#### **Invasive Procedures**

Research commissioned by the Scottish Government in 2010 identified a number of barriers to the delivery of a range of procedures that were essential to the wellbeing of people with profound learning and multiple disabilities. Some of barriers identified in the report<sup>1</sup> included lack of staff training and awareness coupled with policies that do not permit staff to undertake certain procedures.

A key recommendation of the report was to develop a strategic plan for



Scotland that will review and remove the barriers and put in place procedures that will guarantee the delivery of any necessary invasive procedure to any individual who requires it. The Minister for Public Health commissioned an Invasive Procedure Short-Life Working Group.

The task of the Short Life Working Group is to:

- review the recommendations for improving delivery of invasive procedures to children and adults with profound learning and multiple disabilities;
- develop a comprehensive strategy to ensure that all individuals requiring invasive procedures should do so in the care setting to which they are entitled; and
- present the final strategy to the Scottish Government and advise on its implementation, monitoring, review and evaluation.

1. Garrard, B., Lambe, L., & Hogg, J. (2010). *Invasive Procedures: Minimising Risks and Maximising Rights - Project Report and recommendations*. Dundee: University of Dundee.

### **Wheelchair & Seating Services in Scotland**

The review of the NHS Wheelchair & Seating Services 2006 recommended each centre established user and carer groups to provide advice to the centre. PAMIS supported family carers to participate in these groups and in 2011 a report was published which investigated the needs of carers supporting people who use wheelchairs and the impact it has on their health and well-being<sup>2</sup>

2. Roberts, J., Young, H., Andrew, K., McAlpine, A., & Hogg, J. (2011). *Keeping the Wheels Turning: A research project investigating the needs of carers supporting people who use wheelchairs*. Dundee: PAMIS, University of Dundee

### **Emotional Well-being**

In 2005, commissioned research was undertaken by White Top Research Unit and PAMIS to investigate how carers identified changes in the emotional and mental well-being of their sons and daughters<sup>3</sup>. This was a two year research project which produced a report, training workshops which were designed and delivered by family carers with support from PAMIS. A training manual was also produced as an outcome from this research and is available from The Foundation for People with Learning Disabilities.

3. Philip, M., Lambe, L., & Hogg, J. (2005). *Making us count: Identifying and improving mental health support for young people with learning disabilities*. London: The Foundation for People with Learning Disabilities.

### **Bereavement**

Previous research had identified that there was a need for support in the area of bereavement and loss for both people with PMLD and their parents and carers. Our current Bereavement and Loss Project aims to create resources to help explore bereavement and loss with people with PMLD. To date, we have listened to the experiences of parents and carers supporting their bereaved sons and daughters. Teachers from local special schools and paid staff from day-centres also attended these focus groups and this has raised awareness within their workplace as to the loss issues

people with PMLD are experiencing. Published materials from the project will provide guidance on supporting bereaved people with PMLD, for parents, paid carers and professionals. A bereavement conference is planned for later on 2012, in Fife. This conference will also help inform the development of the planned resources of this project.

### **Local and national consultation influencing policy and services**

*PAMIS* has been involved in a number of Council Strategic Planning Groups for Learning Disability Services (SPG's), Partnership in Practice groups (PIP's) throughout the areas we work. These groups bring together local authority, health services, voluntary organisations, people with learning disabilities and family carers, to look at the progression of services for people with learning disabilities. *PAMIS* involvement in these groups has ensured that services for people with PMLD are developed to meet their needs.

### **Further Education**

*PAMIS* provided guidance to the further education sector in their provision for developing meaningful courses for learners with the most profound and complex needs. *PAMIS* shared their expertise and knowledge in effective methods of engaging learners with PMLD. This included methods of assessment and curriculum planning and instruction in the use of multi-sensory story telling techniques. Involvement in this project enables *PAMIS* to encourage local further education provision for people with PMLD<sup>4</sup>.

4. Scotland's Colleges (2012) *Support for Learners with Profound and Complex Needs Project. Final Report*. Stirling: Association of Scotland's Colleges

### **Campaigning**

*PAMIS* campaigns on issues relevant to people with PMLD and their family carers for example Changing Places Toilets. Community Inclusion for people with PMLD is difficult to achieve without the provision of appropriate Changing Places Toilets as highlighted in *the same as you? Consultation report*. *PAMIS* continues to campaign for key public buildings to provide these facilities and to strengthen building legislation. A Directory of all the Changing Places Toilets in Scotland is available to all families and carers.

### **Learning Disability Nursing**

*PAMIS* and family carers contributed directly to the recent UK review on the future of learning disability nursing. We continue to work with NHS NES to ensure that the recommendations of this review are fully implemented<sup>5</sup>.

5. Department of Health (2012) *Strengthening the Commitment: The Report of the UK Modernising Learning Disabilities Review*. Edinburgh: Scottish Government.

### **Postural Management**

*PAMIS* is a partner in the National Postural Care Action Group and have run a number of training courses for trainers and paid carers. Additionally a number of *PAMIS* family carers have undertaken the Postural Care Management Course, Level 1 and a member of staff and 2 physiotherapists have undertaken the full course and are accredited trainers and run courses across Grampian. *PAMIS* is now rolling out this programme in other areas and it is an excellent example of supporting people to self-manage long term conditions.

6. Postural Care Action Group (2012) *Postural care: Protecting and restoring body shape*. London: Mencap

### **Moving and Handling for Family Carers**

A Fife-wide interagency partnership including Fife Carers Centre and PAMIS, together with Moving and Handling trainers and professionals from Fife Council Social Work and NHS Fife won the top award in the Health & Well-being in the community category of the Fife Partnership Excellence Awards 2012. This project is designed to deliver home-based moving and handling training for family carers. This ongoing work should be developed within other local authorities as a priority. This project group was also involved in updating A Carer's Guide to Safer Moving and Handling<sup>7</sup>.

7. Backcare (2011) *A Carer's Guide to Safer Moving and Handling of People 3<sup>rd</sup> Edition*. Middlesex: Backcare

### **Challenging Behaviour**

PAMIS working in partnership with The Challenging Behaviour Foundation provided training workshops in positive behaviour support for parents, teachers, AHPs and day centre staff. This model of training is effective because it offers proactive support, in understanding the function of challenging behaviour in order to reduce the need for physical intervention. This training is delivered jointly by a professional behavioural consultant and a fully trained family carer. Future development of this work is currently being planned.

### **Student Training**

PAMIS is actively involved in the design and delivery of training for social work students, medical students, psychologists and radiographers. PAMIS offers the students the opportunity to experience working with people with PMLD and their family carers in their home environment and in service settings. This invaluable experience enables the students to gain an insight into the lives of people with PMLD and their carers. The students recognise the impact that this experience has on the delivery of their future practice.

'I am more confident in my communication skills. I will know how to behave and communicate when I have a patient with LD and I will share my experiences with others on wards'<sup>8</sup>

PAMIS plans to work with NHS Education for Scotland to take this work forward.

8. NHS Education for Scotland (2012) *The Ryan Harper Legacy: 'A day in the life of...' experiencing influencing allied health professions future practise*. Edinburgh: NHS Education for Scotland.

## **Good Practice - Individuals**

### **Q.5 What have you done, as an individual, to make positive changes within your local area?**

Please provide any comments and/or examples here

Not relevant



## Future Priorities - Healthcare

### **Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?**

Please provide any comments and/or examples here

People with learning disabilities still do not have the same access to health services and health interventions as the rest of the population. People with PMLD have very complex health care needs that are often life-long and enduring. Mortality rate in people with PMLD is much higher than their more able peers with learning disabilities. In the research study noted below, 22% of people with PMLD died during the course of a 10 year longitudinal study. The causes of death were due mainly to their complex and multiple health care difficulties. PAMIS strongly believes that many of these were avoidable deaths<sup>1</sup> which could have been prevented if the individuals' health needs had been recognised and dealt with appropriately. It is vital that there is equitable access to health care for people with PMLD.

1. Mencap (2007) *Death by Indifference*. London: Mencap  
Noted below are the main healthcare needs for people with PMLD:

**Respiratory difficulties:** Respiratory failure is the main cause of death in people with PMLD. Research undertaken by The Whitetop Research Unit, University of Dundee<sup>2</sup>, confirms this finding. There is a need for training for families carers on Respiratory difficulties. Staff in all settings for people with PMLD, eg, schools, day services, residential and respite services, should be trained in recognising respiratory difficulties and have robust protocols to manage these effectively.

2. Hogg, J., Juhlberg, K. & Lambe, L. (2007) Policy, service pathways and mortality: A 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, **51**, 366-376.

**Dysphasia:** Many people with PMLD have problems with swallowing which often leads to aspiration and consequent lung infections. Individual assessment is essential by specialised AHP's to ensure that eating and drinking is managed appropriately to minimise the risks<sup>3</sup>

3. Roberts, J. (2010) Dysphagia: the challenge of managing eating and drinking difficulties in children and adults who have learning disabilities. *Tizard Learning Disability Review* **15**, 1, 14-16

**Epilepsy:** 66% of people with PMLD have severe epilepsy, often not well controlled which results in them rarely being seizure free. It is essential that there are specialised epilepsy nurses in every NHS Board and that medication is reviewed regularly to ensure that the best possible outcomes for individuals.

**Postural Management:** There is a need for accredited trainers to deliver programmes on Postural Management across Scotland to support people to self manage long term conditions. See question 4.

### ***Mental & Emotional Well-being***

There is still a lack of recognition of the impact that changes in mental and emotional well-being has on an individual with PMLD. More training for community health and social care staff in understanding the emotional and mental well-being of individuals with PMLD is required. Access to more individualised and community based assessments for those individuals that require this service should be given a higher priority.

### ***Oral Healthcare***

There needs to be equality in the provision of dental treatment for people with profound and multiple disabilities. The standard of oral healthcare for people with PMLD is generally poorer than that of the general population. There is a lack of routine oral healthcare which if carried out regularly prevents the needs for extractions under anaesthetic and pain relief (often under-diagnosed).

Training and awareness of oral hygiene for social care staff working with individuals with PMLD is necessary. There should be improved access to community dental services through integration of oral health care practitioners into the existing multi-disciplinary team. Specialist training should be available to relevant dental care professionals as recommended by the updated Clinical Guidelines of Oral Healthcare of People with Learning Disabilities<sup>4</sup>.

4. Faculty of Dental Surgery (2012) *Clinical Guidelines and Integrated Pathways for the Oral Health Care of People with Learning Disabilities: Reviewed and Updated 2012*. London: The Royal College of Surgeons of England.

### ***Training for Healthcare Staff***

The training described above that *PAMIS* is undertaking with medical students and Allied Health professionals should be embedded within the training programmes of all health care staff across Scotland.

A key priority is to support health care staff to communicate effectively with service users particularly those with communication needs and to recognise the expertise of carers.

### ***Learning Disability Liaison Nurses***

*PAMIS* strongly believes that learning disability nurses play a crucial role in the health care of people with PMLD. The recommendations made in the recent report of UK Modernising Learning Disability Nursing<sup>5</sup> need to be fully implemented.

5. Department of Health (2012) *Strengthening the Commitment: The Report of the UK Modernising Learning Disabilities Review*. Edinburgh: Scottish Government.

### ***Health Checks***

Equally Well<sup>6</sup> recommended that regular health checks should be provided for all people with learning disabilities. *PAMIS* supports this recommendation and believes that these health checks should be carried out annually.

6. Scottish Government (2008) *Equally Well: Report of the Ministerial Task Force on Health Inequalities*. Edinburgh: Scottish Government

## **Future Priorities - Education**

**Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?**

The design principles of the Curriculum of Excellence are challenge and enjoyment, breadth, depth, progression, relevance, coherence, personalisation and choice for learners. These design features should underpin the development of all school curriculums but challenges to achieving this for children with PMLD within both special and mainstream schools remain. More training is required for teachers in the use of proactive support, in understanding the function of challenging behaviour in order to reduce the need for physical intervention. Better support for teachers in mainstream schools to enable them to deliver more personalised support for learning. There also needs to be an improved transition process that makes better use of the Co-ordinated Support Plan for individual children. Currently the information provided in the support plans is often not used to help design future support plans for children moving into adult services. Better use of information sharing at this crucial time should be encouraged and a process that allows meaningful use of this information needs to be part of the transition process. Ongoing training for teachers in communication and the use of multi sensory techniques will ensure that the design principles of the Curriculum of Excellence are accessible to all pupils with PMLD.

### **Further Education**

There is an urgent need for colleges to improve the learning environment in terms of both the physical and intellectual access to enable students with PMLD to participate in more meaningfully in further education. Courses should be based on principals of meaningful learning provision, as defined by Scotland's Profound and Complex Needs project team. This project has made great strides in really listening to family carers and professionals supporting them and in ensuring they now offer courses that are accessible to people with PMLD. However, the funding for this highly important work has recently come to an end. PAMIS would like to see the excellent work of the project team to not only continue but expand.

The college environment should be designed to enable people with complex needs to access courses appropriate to their individual needs, for example provision of quiet areas for students who often find the college environment too noisy and overpowering. Appropriate Changing Places toilets should be available on every campus and access to technology that will allow improved access to meaningful learning e.g. Communication switches.

## **Future Priorities – Independent Living**

**Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?**

PAMIS fully supports the rights of people with learning disabilities to live independently and that they provided with whatever level of support to enable this to happen. We also recognise and acknowledge that people with profound and multiple learning disabilities will never be able to live independently. However, we do support their right to live as independently as possible but prefer to use the term, *Supported Living*, which more accurately describes their needs and the preference of their parent carers. We ask that the Scottish Government and those responsible for the outcomes of this SAY Consultation recognise and use this term as well as that of *Independent Living*.

It is recognised that most incidents of harm and abuse of people with learning disabilities occur in managed settings. Research has shown that people with PMLD suffer higher levels of abuse/harm than their more able peers with learning disabilities<sup>1,2</sup>. Family carers are aware of this and one of their major concerns when considering supported living options is regarding the protection of their son/daughter once the move from the family home. We need to ensure that all people with PMLD are protected from harm throughout their life. There are examples of excellent sheltered accommodation provision for people with PMLD but there is not nearly enough.

1. Campbell, M., Cullen, C., Hogg, J. & Hudson, W. (1997) *Approaches to Sexual Abuse of Adults with Learning Disabilities: an open learning course for direct care staff working with people with learning disabilities*. St Andrews: University of St Andrews.
2. Whorisky, M., Green, A. & Mackay, C. (1993) *Consenting Adults?: Sexual Abuse and Adults with Learning Disabilities: A Framework for Practice Guidelines*. Glasgow: ENABLE.

To fully meet the living of people with PMLD in adulthood when it is appropriate and timely for them to move from the family home the following requirements must be in place:

**Accessible housing:** Housing that is fully accessible with the following specialist equipment, preferably built-in, not added on extras: Ceiling tracking hoists; wet rooms; accessible toilets; ramps as necessary; height-adjustable beds, chairs etc that are based on the individual's assessed needs; open space to garden or patio that is wheelchair accessible

**Trained staff:** there must be the correct ratio of staff per resident. People with PMLD require a minimum of on-to-one support at all time, that is 24-seven 52 weeks of the year. Staff must be trained in all individual's healthcare needs, including administration of medication, with agreed protocols for each procedure or intervention and competent staff trained to deliver and monitor all these interventions.

**Day and leisure opportunities:** A full programme that meets the individual's day opportunities and social needs must be fully included and costed into the package of care.

**Partnerships with parents/carers:** The care provider must recognise the rights of the parent to be involved in the person's life once they move from the family. Many parents or relatives are Welfare Guardians for their son/daughter with profound and multiple learning disabilities, however, this is often ignored or not recognised by residential care staff.

**Single tenancies and small group homes:** The families should have a choice over the type of accommodation for their daughter/son with PMLD. Many families prefer a small group setting, ideally two residents, but no more than three and the parents (or close relative if parents are no longer there) of each individual should be involved in selecting the care provider, the staffing levels, training of staff, and involved in developing the protocols for their own son/daughter. Some families may opt for a single tenancy arrangement but it should be their choice and not the only option available.

**Protection of the adults:** The care provider must evidence that there are robust adult support and protection policies in place, coupled with effective training for staff in these policies. Parents/carers should be informed of these policies and given access to these and other relevant procedures as a matter of course.

### **Future Priorities – Employment**

#### **Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?**

Please provide any comments and/or examples here

People with PMLD have limited opportunities for employment. *PAMIS* will continue to work with local authorities to explore enablement opportunities for people with PMLD.

### **Future Priorities**

#### **Q.10 What other future priorities do we need to focus on? (Please list these in order of importance with the most important first)**

Please provide any comments and/or examples here

##### **Value of people as citizens.**

All people with a learning disability are full citizens, equal in status and value to other citizens of the same age. With the focus of both health and social work services shifting to a more person centred delivery model, there is a need for a robust framework that measures the quality of the delivery of these personalised services. A robust framework with a strong values base will ensure that services do actually place the person at the centre of care and will help ensure personalisation is more than simply a theoretical exercise.

There needs to be ongoing improvements in healthcare, education,



provision of accessible leisure, improved training and education of social care and health care staff and improved recognition for the expertise of family carers in order for people with PMLD to be full citizens, equal in status and value to other citizens of the same age.

**Maintaining the value of Benefits, to ensure person centred care is delivered to people with PMLD.**

There needs to be recognition of the cost of care packages for people with PMLD (because of their need for 24 hour care, and often 2: 1 support, and their complex health needs (PEG feeding, postural difficulties etc), too often not enough money is made available in social work teams or health budgets to adequately support people with PMLD because of the costs of their care. With the forthcoming changes in the delivery of care and changes to the benefit system there needs to be improved understanding of the needs of people with PMLD and the assessment process should ensure these needs are fully considered. The cost of care provision for people with PMLD should not exclude them from accessing personalised services, tailored to meet their needs. An adequate resource allocation system with emphasis on quality of service provision is required to ensure that people with PMLD have the opportunity to benefit from the personalisation of services.

**Thank you for taking the time to read the consultation document and taking the time to respond to the question. Your continued input and support is vital in ensuring that we continue to close the inequality gap that people with a learning disability face daily.**

**All completed questionnaires should be returned to Sarah Grant either by e-mail or at the address below. The closing date for responses is 30<sup>th</sup> September 2012.**

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