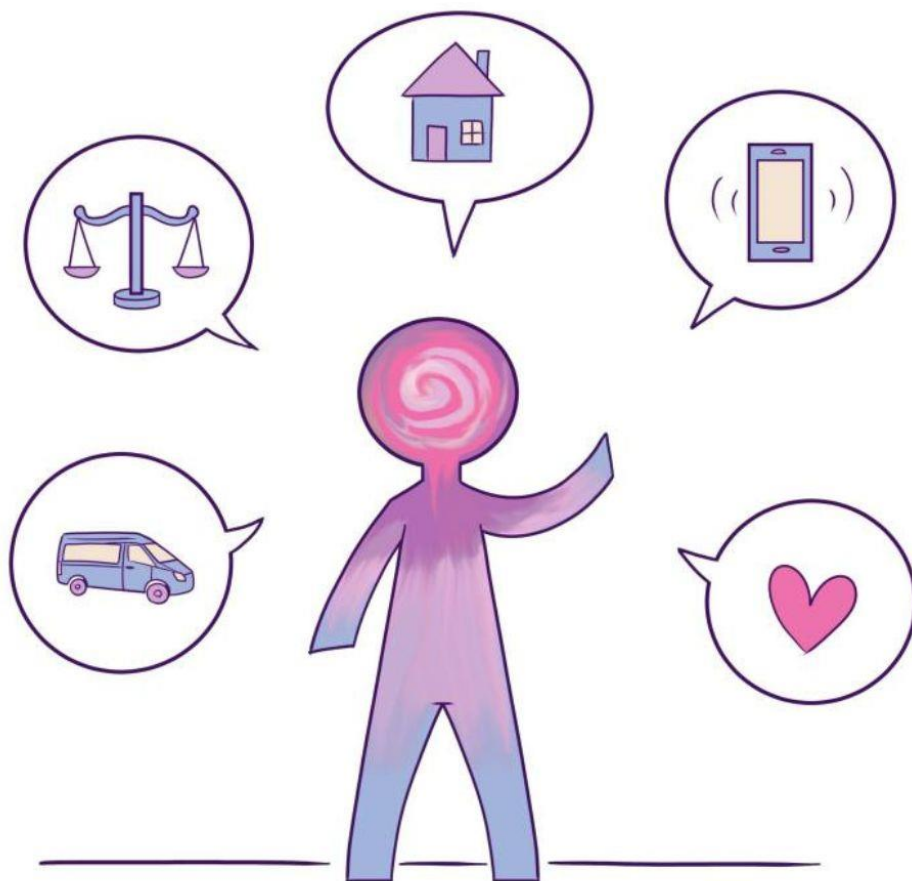




Learning Disabilities, Autism and Neurodivergence (LDAN) Bill Consultation Response

21 April 2024



Contents

Introduction.....	3
Part 1: Reach and definitions: who should the Bill include?	5
Part 2: Overarching Themes	9
Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities.....	9
Section 2: Mandatory Training in the Public Sector	12
Section 3: Inclusive Communications	15
Section 4: Data	19
Section 5: Independent Advocacy	26
Part 3 - Specific Themes	29
Section 1: Health and Wellbeing	29
Section 2: Mental Health and Capacity Law	45
Section 3: Social Care	48
Section 4: Housing and Independent Living.....	57
Section 5: Complex Care, Coming Home	61
Section 6: Relationships.....	64
Section 7: Access to Technology	70
Section 8: Employment	72
Section 9: Social Security	74
Section 10: Justice	77
Section 11: Restraint and Seclusion	80
Section 12: Transport	81
Section 13: Education	85
Section 14: Children and Young People, Transitions to Adulthood	90
Part 4 – Accountability	96
APPENDIX.....	102
Transition Case study Fife.	102

Introduction

PAMIS, promoting a more inclusive society, is the only charity that solely supports children, young people and adults with profound learning and multiple disabilities (PMLD) and their families to lead healthy, valued and included lives. PAMIS has spent 32 years listening and working with people with PMLD and their family carers building research and practice that supports this group to be included and valued within society albeit slowly and with much still to be done. PAMIS is recognised nationally and internationally for the work it undertakes and has led the world in work in relation to areas such as bereavement and loss, emotional well-being, multi-sensory storytelling, inclusive culture and leisure, lifelong learning for people with PMLD and as the cofounder of the changing places toilet campaign.

People with PMLD and their families are some of the most excluded within our communities, and currently some of the most isolated. Caring is an intensive and isolating role; many family carers provide this 24/7 with little, if any, respite. However, PAMIS recognises that profound means deep wise, expert. This group of people never cease to amaze us with their contributions and PAMIS ensures that they and their families are recognised and valued for this contribution. Their role in education of communities and practitioners in how to care, how to act with compassion, how to communicate, how to be solution focussed and importantly how to work together is essential if we are to develop inclusive communities. Only when we bring together the expertise and knowledge of a whole team including the person with PMLD, and their family carers do we begin to understand the needs of this marginalised group of people and develop ways to ensure they realise their dreams and potential.

PAMIS are therefore passionate about the specific inclusion of people with PMLD in the Learning Disabilities, Autism and Neurodivergence Bill. Our approach in responding to this consultation has been to draw on the views of the many families we have worked with over the 32 years and from our engagement with people with PMLD through our specific resources and specialist staff. This has entailed months of desktop work ensuring that we were capturing what we have been told over the years and then reengaging on what we had heard to ascertain if these were still the key issues. Sadly, many of the issues experienced decades ago remain. This is driving our commitment to ensure that people with PMLD and their families are brought out of the shadows and become a priority for any Bill going forward. This group of people have been neglected, ignored, and made invisible, often because

the expectation is that they will not live into adolescence or adulthood because of their disability, so why bother? With advances in medical care and support from dedicated research as well as best practice guided by family carers, this is no longer the case and many people with PMLD can live an active and valued life into adulthood and beyond. We want this narrative to change and an expectation of living into adulthood and beyond to be placed on all public bodies and within our communities, so we plan for inclusion of this group, provide hope instead of despair, and honour the human rights of the most marginalised.

We were unable to find any section within the consultation that did not require comment. Our thoughts and conclusions are frequently raw, voiced by the people we have the privilege to support and provided with passion and a commitment to be part of any ongoing conversations and actions required.

People with PMLD teach us all how to listen with all our senses, to reflect on our and other behaviours and communication, to be creative, innovative, be open to new thinking, but above all to be humble and recognise that no one person has the answer but if we use our collective wisdom, we might just get it right.

Jenny Miller
CEO PAMIS

Pat Graham
Chair of PAMIS Board

Part 1: Reach and definitions: who should the Bill include?

Proposal 1: People who are neurodiverse and neurodiverse people.

Proposal 2: People who are neurodivergent and neurodivergent people.

Proposal 3: Highlighting specific conditions only in the Bill.

Q1. Which of these proposals do you agree with (if any), please tell us why?

PAMIS agrees with proposal three.

People with profound learning (intellectual) disability and additional complex multiple disabilities (PMLD) are a diverse group of individuals with their own personalities, preferences, and ways of communicating. The abilities of those described as having PMLD vary considerably and not least because of the varied life experiences they may or may not have had. They are one of the most marginalised group of people in society. Due to the multiplicity of their disabilities, they are often excluded from playing a full role in society, primarily because our communities are not inclusive, or not inclusive enough.

Profound means deep, intense, wise, requiring great insight or knowledge and although many people with PMLD have significant areas of disability described below they also have unique areas that never cease to surprise those who care and work with them. The description below is the science, a medical approach, but the experience of being a part of their lives is something very different. The description below also misses the unique contribution people with PMLD make to the lives of others, not least in what they are able to teach about how to care, how to act with compassion and how to make human connections.

People with PMLD clinically share a number of characteristics that make this term appropriate and leads to challenges for them and those who support them. Their prime disability will be profound learning (intellectual) disability. The causes are many and varied. All have had some form of damage to their brain and central nervous system. This may be caused by injury before, during or after birth, by genetic factors, by infection to them or their mother, or by accidental or non-accidental injury. Whatever the cause, and this sometimes goes undiagnosed, their development as children and adults is severely constrained. Few achieve the cognitive and communicative abilities of a two-year-

old, and clinically they are described as having an intelligence quotient less than 20 (IQ<20), hence “*profound learning disability*”. The physical and sensory disabilities that arise from damaged brain function will also restrict their interaction with the world (the “*multiple disabilities*” referred to) making them highly dependent on others to ensure that they have the opportunity to experience the value of life that others take for granted. The majority will be life-long wheelchair users. The combination of intellectual, physical, and sensory difficulties is often compounded by significant health problems, including epilepsy, respiratory and nutritional difficulties, resulting in many being fed non-orally.

The majority of people with profound and complex disabilities live at home with their parents. Research¹ has shown that family carers spend on average 8.5 hours per day on basic caring tasks. It is difficult for people with PMLD to access activities in their communities because many facilities are not accessible or inclusive. However, we do know that with the correct help, support and resources that are truly accessible, people with PMLD can and do take an active role as participants in their communities.

We highlight the definition above because this group of people remain invisible within our communities and therefore facilities and services are not developed to enable them to lead healthy, valued, and inclusive lives. If you don't see people within your community or have no experience of caring, why would you consider the development of a changing places toilet? And if you believe that a child will not grow into an adult, why would you invest in facilities and resources? These are the battles families have on an ongoing basis. As a result, PAMIS' greatest concern is that PMLD is not specifically named and defined within the bill.

People with PMLD and their families felt invisible, abandoned, and forgotten during the COVID 19 pandemic and in many cases, this remains as services have not returned to appropriate levels. The lack of understanding about the complexity of care and the intense caring role is obvious. People with PMLD are already a subgroup of a subgroup within society, and within a wider group of neurodivergent people there is a real fear that they will be completely disappear.

People with PMLD can thrive and contribute to all our lives but it takes all your senses to listen and understand them and it takes time to develop their skills and contributions. This needs to be specifically spelt out and their uniqueness celebrated. Unless specifically named/mentioned as a

¹ *Living Healthy, Living Well – supporting the physical health and wellbeing of people with profound and multiple learning disabilities*, NHS Education for Scotland, 2016.

group we believe this group will continue to be marginalised, ignored, and remain invisible.

There are many unnamed syndromes that lead to a profound learning disability. Children often wait many years for a specific diagnosis. People with PMLD will have a range of other conditions that require to be seen in their own right so that the risk of diagnostic overshadowing is minimised. During COVID these underlying health conditions were not registered putting individuals at further risk, not being able to access the shielding opportunities and again facing invisibility.

PAMIS must have full assurance that the LDAN Bill will not include so many different people who are deemed neurodivergent that it will not be able to adequately support anyone. People with PMLD are already invisible in policy and communities. PAMIS needs assurance that their very specific needs and assets will be seen and fully supported.

PAMIS want the specific naming of people with a profound learning and multiple disabilities and their families as a group to be supported by the Bill. Although a part of the learning disability community there are distinct differences in support and opportunities for this group. As part of this we would like to see specific acknowledgement within the bill of the positive lives people with PMLD have, and the contributions that they make to all our lives and the communities they live in, when they are enabled to do so.

It is also important that there is recognition that people with PMLD will also have other health conditions that require to be seen in their own right, that people with PMLD are identified and planned for across the age spectrum – there must be a culture change towards an expectation of living, and including clearly defining PMLD within the bill creates more opportunity for this change to occur.

It is important that there is support within the proposals for those awaiting diagnosis and where there are delays in assessment, an assurance that they will still be covered by the Bill.

Clarification that the definition of PMLD occurs before adulthood, as supported by the definition of a learning disability, but which is then confused by part 1 of the proposals - that Acquired Brain Injury happens after birth and will therefore not be included within the scope of this bill. This is of great concern to PAMIS as, by not including acquired brain injury, this would impact on some children and young people who are currently seen as a person with PMLD.

Q2. Which of these proposals do you not agree with (if any), please tell us why?

PAMIS does not agree with proposals one or two.

Q3. Is there anything else that we should consider which is relevant to this topic?

Not applicable.

Part 2: Overarching Themes

Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities

Proposal 1: Introduce a requirement for a national strategy on learning disabilities and neurodivergence to be produced by the Scottish Government.

Proposal 2: Introduce a requirement for local strategies to be produced by some public bodies, for example health and social care partnerships, local authorities, and other public bodies.

Proposal 3: Introduce guidance that could cover a range of topics to be included in national and local strategies.

Proposal 4: Ensure that there is a requirement to review strategies, for example every 5 years.

Proposals 5: Ensure that people with lived experience have to be involved in the development of the strategies.

Proposal 6: Consider whether any new accountability mechanism introduced by the Bill should have a duty to review national and local strategies and their effectiveness.

Q1. Which of these proposals do you agree with (if any), please tell us why?

PAMIS agree with all the proposals in principle but if we look back at the impact locally and nationally of strategies both specific and broader, on the outcomes for people with PMLD and their families we would question whether the amount of resource taken to develop them was worth it.

People with PMLD and their families are currently in the most difficult position they have ever been in. There are limited services, little or no respite, limited social workers, health services who withdrew during the pandemic and have not returned to support the damage done. The time is not to contemplate more strategies, it is to do what we know needs doing, it is to take action and implement what is required.

For people with PMLD, health outcomes are poor no matter where they are. What they don't need is 32 different interpretations of what this means and what action is required, they need evidence to be put into practice, practice to be shared, improvements to be made and collaboration across health and social care and with the third sector.

For 32 years PAMIS has been working with people with PMLD and their families and their asks and aspirations have not changed over these decades. We must build on the decades of consultations, research, and evidence of what is needed and what works. We continually visit areas where it is known what needs to happen.

It took us 20 years to get the changing places toilets into legislation and we still only have 256. A changing places toilet is such a basic human right and lack of having a facility to have personal care needs met with dignity and respect means that for many people and their families there are no visits to friends, no going out to the cinema, no keeping fit and having fun at the local swimming pool, no visits to the theatre. The Keys to Life Strategy² ensured that there were 100 changing places toilets developed and while this was welcomed it was a drop in the ocean and a token contribution to the lives of people who are some of the most excluded within our communities.

So, our question is what difference will the next strategy make? And how do we interweave it with the Derek Feeley Independent review of Adult Social Care in Scotland³ that had at its heart the voices of the people of Scotland? PAMIS and the families we support provided a detailed response⁴ to this and the development of the National Care Service. It provided hope for a future, a change in the narrative. It also provides guidance for what is required going forward. If this extensive piece of work is struggling to convince the 32 local authorities to work differently it is difficult to see how we can move forward in Scotland to make a difference.

However, the families that PAMIS support are keen to be part of the solution. They and their relative with PMLD have untapped skills and passion that can move ideas and concepts into action. What they want is the opportunity to support strategy becoming a practical reality in practice. This should be harnessed going forward, with people with PMLD and their families alongside people with a learning disability involved in planning the action to implement the changes in practice that we know will make a difference. Review and evaluation are essential not in a 5-year cycle but the adoption of an iterative process to ensure that progress is being made and change is being implemented. Family carers and people who use services are the ones with the vested interest in change and improvement and therefore should be engaged in ensuring it is happening. They should have a supervisory role with

² *The Keys to Life – Improving Quality of Life for People with Learning Disabilities*, The Scottish Government, Edinburgh, 2023.

³ *Independent Review of Adult Social Care in Scotland*, The Scottish Government, Edinburgh, February 2021 .

⁴ *A National Care Service for Scotland – Consultation*, The Scottish Government, August 2021, *Response ID 759825833*.
pg. 10

senior officers who need to be accountable to them for decisions made, progress, and any identified issues.

PAMIS agree that local authorities will require support and guidance to ensure they are planning and delivering appropriate services and support for people with a learning disability, for autistic people for neurodivergent people and we would advocate for there to be naming of specific groups because without being identified invisibility lingers. Many local authorities will not recognize people with PMLD and their families as a group with very specific needs and do not have the necessary skills in engaging them in their consultations and reviews. Support and education will be required to change a culture that has been allowed to exclude people and to then erode their human right to have a life of meaning, of inclusion and to have the right to have a life with necessary health treatments. We are concerned that currently guidance has very little impact on practice so we would suggest that proposal 3 will not get the traction required and will lead to further frustration from the people it seeks to support.

If a national strategy is developed it must influence and complement other national work and strategies. We believe that the Scottish Government should promote and ensure that there is cross government collaboration and that the most marginalised are always considered in the development of future strategies nationally and locally. If something works for a person with PMLD very frequently it will support many more.

Q2. Which of these proposals do you not agree with (if any), please tell us why?

n/a

Q3. Is there anything else that we should consider which is relevant to this topic?

n/a

Section 2: Mandatory Training in the Public Sector

Proposal 1: Mandatory Training for Public Services

What do you think?

Fundamental to any improvement and changes in outcome for people with PMLD, autistic people and neurodivergent people is the ability to reach the current and future workforce. We have highlighted throughout our responses the need for training and support for the health, education, social care and broader public sector workforce but also a wider connection with communities in which people with PMLD live.

Do you agree with this proposal? If so, please tell us why?

Although PAMIS agree with mandatory training we feel that how this is delivered and embedded in practice requires to be considered. Experiential learning, support for reflection in and on practice, ongoing support and supervision are essential if learning is to make any difference. We are concerned some educational resources do not provide all of these ingredients and therefore do not go far enough in changing practice or culture. We also believe that the training needs to include a wider public sector group.

Currently there is very little training available to support people in understanding the lives of a person with PMLD. This includes a lack of knowledge about the value of their life, how to involve and include them and also how to support their very complex needs. There is also no training to support any understanding of the role of the family carer and the impact of very intensive caring on their health and wellbeing. PAMIS want to see mandatory training specifically about this group of people and their families. We also want this to include postural care courses. We agree that training should be co-designed and delivered in partnership with families, but we also believe they should be involved in the evaluation of impact of the training. We feel that this should go further and in terms of a social care workforce, we think that families of people with PMLD should define the knowledge, skills and values required to work with children, young people, and adults with PMLD. They should then be involved in the design of the curriculum, the learning outcomes and support delivery of training as well as playing an essential role in any evaluation. This would provide families with assurance about the care that a future workforce will deliver to their loved one.

PAMIS also believes that more can be done to ensure those considering a career in health, education, or social care or indeed wider, have skills, knowledge and attitudes required to be a part of a more

inclusive and caring workforce. We suggest mandatory volunteering courses in the sixth form with third sector organisations supporting people with PMLD or other groups.

If you disagree with this proposal, please tell us why?

n/a

Is there anything else that we should consider in relation to this topic?

We believe that models that are currently being developed by PAMIS have the opportunity to influence attitudes, reduce stigma, create inclusive and kinder communities. We also believe that people frequently do not mean to exclude they are just unaware of how to engage with people with PMLD and how to be inclusive. Access to learning with and from people with PMLD and their families is a solution to develop insights and understanding.

PAMIS provides a range of training that supports understanding, skills and values development. Our model of family carers and people with PMLD co-delivering courses have been highly successful in changing attitudes and encouraging team working, including working with family carers as core members of the team. For the last decade we have supported the education of the next generation of health and social care practitioners through practice placements within PAMIS. People with PMLD and their families have provided the learning opportunities, recognised as the best educators in terms of teaching us all how to care, how to act with compassion, how to listen and really hear and how to work collectively and collaboratively. Our developing lifelong learning model offers a broader group of students across many disciplines an opportunity to learn alongside people with PMLD influencing practice and attitudes in a wider societal and community context.

PAMIS are proposing the development of a PMLD hub in each HSCP where the specialisms relating to PMLD can work, research, and learn together. There will be the opportunity to share best practice and scope to identify the interrelated and interdependent medical, physical, emotional and behavioural issues relating to the individual with PMLD. This will be an ideal training ground for health and social care practitioners working with people with PMLD and an opportunity to train others. In addition, the skills of the family carers would be shared as co-trainers in all aspects of information, that will break down the lack of inclusion and discrimination. People with PMLD will also be vital tutors, enabling people to learn from their lived experience, such as the Ryan Harper⁵ experience and coordinated

⁵ *The Ryan Harper Legacy: 'A Day in the life of...' experiencing influencing allied health professions future practice.* Edinburgh: NHS Education for Scotland. 2012.
pg. 13

practice placements. At PAMIS we provide placements for students from many disciplines who often arrive with limited knowledge of PMLD but who invariably depart with a new-found respect for people with PMLD and their families. They are often sufficiently motivated and inspired to reconsider their career direction, as a consequence. PMLD Hubs would be the ideal environment to nurture such careers.

Section 3: Inclusive Communications

Proposal 1: Alternative means of communication

Proposal 2: Easy-read.

Proposal 3: Neurodivergent and learning disabilities strategies.

Proposal 4: An enforceable Accessible Information Standard for Scotland

What do you think?

Profound means deep, wise, and expert and people with Profound learning and multiple disabilities are some of our best educators teaching us how to care, how to act with compassion, how to be inclusive and how to work together. People with PMLD are also some of the most complex and marginalised members of society. They often don't communicate verbally or in a way that we readily understand. If we are to truly support them to lead valued and inclusive lives, we must try to be experts in understanding them, their communication and the ways in which they interact with the world around them.

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: Alternative means of communication

The communication methods required by people with PMLD vary widely depending on the nature of their disability. PAMIS' main views on inclusive communications centre around the need for far greater flexibility to accommodate families caring for someone with PMLD whose intensive caring role can often impact their ability to attend in person meetings or appointments at short notice. The role of the family carer as expert in understanding the communication needs of people with PMLD is central to any information transfer relevant to the lives of those with PMLD. Caring for a person with PMLD is an intensive and isolating role; many family carers provide this 24/7 with little, if any, respite. It is very difficult for a person with PMLD to visit many public buildings and offices due to the lack of appropriate changing places toilets available. Letters and correspondence relating to the various health, social care and education appointments are often difficult to understand, unnecessarily complicated or do not contain the key information at a glance such as the direct number to call. PAMIS have developed digital passports⁶ as a key tool to facilitate inclusive communication, which could provide an effective solution for professionals to better understand the needs of people with

⁶ <https://pamis.org.uk/services/digital-passports/>

PMLD and their families and we have detailed more about this model of working in the access to technology section. It is essential that a basic understanding about the reality for carers with such an intensive caring role is more widely understood and that it is often very difficult for them to attend appointments or to take unexpected phone calls throughout the day therefore it is important to understand the challenges facing people with PMLD and their families in regard to communications. Ongoing training of public bodies in the many varied ways people with PMLD engage with information would be welcomed by PAMIS as there is currently a lack of understanding of the various ways people with PMLD can be supported to engage with information.

Multi-sensory storytelling is one way of helping someone understand information for those who find it difficult to communicate verbally. Sensitive topics such as growing up, life transitions, preparing for hospital appointments or hospital admissions all can be supported by storytelling for individuals. If information was to be conveyed through this methodology awareness training would be necessary as it takes time to convey information via this method however if information was streamlined and conveyed in an easy to understand format then families and support staff could then create stories that would help people with PMLD to engage with information on a more meaningful way relevant to them as individuals.

Proposal 2: Easy read.

PAMIS agrees that there is a definite need for improved access to information for people with PMLD and their families produced by all public facing bodies. This information should be produced in jargon free language and is easily to access, understand and relate to. People with PMLD usually present with a very limited learning capacity (functioning at around the age of 2 years, even if they are an adult) so no written form of information would be accessible to them. People with PMLD are reliant on their family carers to interpret at an appropriate level all communication and information they require. If the person lives in supported accommodation this role would be provided by their staff team and still often involves the family carer. However, video and audio explanations/footage, as well as easy read materials, can be a useful alternative means of communication for family carers. Most family carers have a huge care role, making life already stressful and challenging for them, so anything that can ease this situation will be extremely helpful.

Proposal 3: Neurodivergent and learning disabilities strategies.

PAMIS supports the requirement of national and local strategies to be produced and applied to all local authorities and public bodies as currently the understanding of how to convey information to

people with PMLD and their families is varied and is actually the cause of many unnecessary problems. PAMIS acknowledges that public bodies currently deal with a wide and varied range of people with various health issues and disabilities. However, if information was uniformly provided and conveyed in a standardised form that explained why people had to have information delivered in ways that were relevant to them this would ease the current stress that many face through lack of understanding the information in policies and procedures. Delivery of verbal information to people with PMLD and their families ought to be considered and included in any information policy as misunderstanding of verbal information is one of the highest causes of stress, anxiety, and declining emotional well-being of both people with PMLD and their families. Again, training and development in how best to convey information to people with PMLD and their families would significantly improve information and knowledge transfer.

Proposal 4: An enforceable Accessible Information Standard for Scotland

PAMIS supports the proposal for an Accessible Information Standard to be enforceable and welcomes the requirement for its implementation and impact to be reviewed. The standard. PAMIS would hope that any future accessible information standard would highlight and include how to communicate with people with PMLD as currently they are not included in any provision of information.

Q2. Which of these proposals do you not agree with? please tell us why?

n/a

Q3. Is there anything else that we should consider which is relevant to this topic?

EXAMPLES OF TOOLS TO SUPPORT INCLUSIVE COMMUNICATIONS

Communication

I can:

- Recognise familiar objects, photos and pictures
- Point to things that are near to me with my fingers and hand. I use my vocalisations and facial expression to communicate. I use some gestures and signs to tell you things.
- Point to pictures in my communication book to tell you what I want


This was what I used to do to interact but I can't really do this now because I am not strong enough to press my switch any more.

Storytelling over time:

- Someone would place the voice output switch on my tray or table where I could reach it during a story or song. The switch would stay there until the end of the activity - that helped me to learn how to use it at the correct time. I might have pressed it lots of times during the story but I was still learning when to press it and it was very exciting. When it came time for me to "say" my line, the person supporting me would pause and give me time to press the switch. They gave me lots of praise when I got it right and they ignored me when I pressed the switch at different times. I can't do this any more but I still love stories.

Big Mack Switches

This simple communicator has lots of uses! It's easy to record speech, music or any sound into the **BIGmack**. Record a repeated phrase from a story or song for me to play back at the right time. I loved doing this but I'm not so able to do it now.



[Digital Passports: A way to tell your own story - Health and Social Care Alliance Scotland \(alliance-scotland.org.uk\)](https://alliance-scotland.org.uk)

['Seen, Heard, included' Report - Supporting meaningful engagement and participation - Health and Social Care Alliance Scotland \(alliance-scotland.org.uk\)](#)

[PAMIS Digital Passports | PAMIS](#)

People with PMLD can be supported to have a voice using their Digital Passport if they have one. The Digital Passport supports and enables people with PMLD to be more fully involved in any communication about their lives, it helps them to be included and enables and supports them to participate in discussion about them.

PAMIS also recommend that more resource is put into supporting people with PMLD to engage with services and to understand the services being offered or procedures being required. The PAMIS library of multisensory stories including the sensitive stories, is one approach that could be used. We also highlight the engagement tool [I Can If You Can.](#)⁷

⁷Part of *Seen, Heard, Included - Meaningful engagement with disabled children and young people with complex needs and their families*, The Health and Social Care Alliance Scotland, August 2023
pg. 18

Section 4: Data

Proposal 1: Developing a commission(er) with responsibility for data collation.

Proposal 2: Placing duties on some relevant public bodies to collect data on neurodivergent people and people with learning disabilities.

Proposal 3: Placing duties on some relevant public bodies to provide returns to the Scottish Government regarding local data on people with learning disabilities.

Proposal 4: Consideration of the development of a Scottish version of the LeDeR programme

What Do You Think?

PAMIS have for many years questioned the inability to accurately identify the numbers of children, young people and adults with a profound learning and multiple disabilities (PMLD). We believe this has maintained the invisibility of this group, has hindered progress in their inclusion in communities and has been an excuse to not develop services or resources. At worst we believe it has led to avoidable and preventable deaths and has placed unmanageable burden on the families who frequently provide intense, prolonged care for the life of the individual with PMLD.

During COVID many people with PMLD were not identified for the shielding list even though they presented with several of the qualifying at-risk conditions. Who held the data on these individuals? How were they coded? Were their co-morbidities noted/coded? Who cared? Without the necessary data on these individuals how could the right decisions be made within a pandemic?

We continue to search for the answers to these questions but have recently identified a significant barrier to the quest for visibility within the data. People with PMLD are not expected to live. Death reviews were not carried out on children and young people with PMLD until 2 years ago because it was an assumption that they would die from cerebral palsy and in their early years. Therefore, there has been no appetite or interest in identifying these individuals and including them in plans for their adulthood. Without a public outcry they would have been on the clinical frailty scale for no treatment in the early stages in COVID because of this negative narrative about not being expected to live, or as awful not being seen to have a valuable life.

This narrative must and will change. People with PMLD do not die of cerebral palsy they die because the right intervention and early preventative measures are not put in place. Sometimes the cause of

death is identified as “learning disability” as found in SLDO research⁸ and the serious concerns about diagnostic overshadowing. People with PMLD can lead valued, healthy, and inclusive lives and into adult hood. This is usually because their family carers equipped with knowledge, innovation and creativity are ensuring their relative does have access to preventative measures such as postural care.

So now is the time to develop the data to support the planning, to focus the research, to innovate practice, to value a group of people who have for too long been neglected. The data needs to support visibility and therefore people with PMLD require to be identified separately within the data about people with a learning disability. Their multiple other disabilities and conditions also need to be visible and part of the data collection. This data will be a positive step towards reducing inequalities, preventing avoidable death and planning for life.

Q1. Which of these proposals do you agree with? please tell us why?

PAMIS agrees with both proposals 2 and 3.

Placing a duty on relevant public bodies to collect and report on data in relation to people with learning disabilities and neurodivergent people is essential if we are to progress positive outcomes for these groups. PAMIS would like this to go further and for people with PMLD to be identified and visible within the data. Their invisibility must be addressed urgently to reverse the decades of inactivity because of the expectation that they would die early and before reaching teenage and adulthood. This narrative will change and people with PMLD are living as adults. We therefore need the explicit data on them to begin planning for their positive future.

We recognise that if there was effective data collection and sharing at an early enough stage the impact on the transitions of people with PMLD could be enhanced. Essential to effective transitions is the understanding of the complexity of need, the numbers of young people with complex care needs coming towards transition and their aspirations. Sharing this data at an early enough stage allow for adequate housing, workforce planning, service provision for lifelong learning opportunities and short breaks/respite, as well as specialist healthcare.

⁸ *Early death and causes of death of people with intellectual disabilities – a systemic review*, O’Leary, Cooper, Hughes-McCormack, 2017.
pg. 20

Having a tangible focus for sharing information will grow the confidence in families about releasing their data. There are decades of mistrust to be overcome and the PAMIS digital passport has been a tool to enable families and the person with PMLD to gather their own data and then they choose who they share it with. Building on this approach and resource for future health and social care sharing would be useful.

PAMIS are concerned, however, that the proposals in the LDAN Bill do not have a specific plan for enhancing analytical resources. To be effective, improved data collection will require clear guidance to be produced, collection methods will need carefully considered and quality assurance processes developed. Enhancing the evidence base through the collection of more relevant data is only going to be truly worthwhile if there is investment in the analytical capacity to robustly collate and analyse this information. At present it is too limited.

We are also not clear on how these proposals will interact with annual health check data and this needs to be clarified. Ultimately, resourcing requires to be boosted along with more opportunities to bring expertise together (as opposed to working in silos which is currently the case) if we are to ensure data improvement work can thrive long term and be sustainable.

Proposal 4: Consideration of the development of a Scottish version of the LeDeR programme

PAMIS note that there is no mention of the Scottish Government Child Death Review Process⁹ introduced in October 2021 and supported by the National Hub for reviewing and learning from the deaths of children and young people -

<https://www.healthcareimprovementscotland.scot/inspections-reviews-and-regulation/national-hub-for-reviewing-and-learning-from-the-deaths-of-children-and-young-people/>

National hub background and reporting

Scotland has a higher mortality rate for under-18s than most other Western European countries. Over 300 children and young people die each year. Around a quarter of those deaths could be prevented.

Summary

⁹ *National Guidance – for child protection committees undertaking learning reviews*, Scottish Government, Edinburgh, 2021
pg. 21

Reviews will be conducted into the deaths of all live born children up to the date of their 18th birthday. This extends to 26th birthday for care leavers. These care leavers are in receipt of continuing care or aftercare at the time of their death.

The National hub aims to:

ensure that the death of every child in Scotland is subject to a quality review by:

- developing a methodology and documentation to ensure all deaths of children and young people, that are not subject to any other review, are reviewed through a high quality and consistent process.
- improving the quality and consistency of existing reviews
- improve the experiences and engagement with families and carers.
- channel learning from current review processes across Scotland that could direct action to help reduce preventable deaths.

Admittedly this was introduced during the pandemic and indeed PAMIS only became aware when a family was contacted out of the blue about the review of her son who had sadly died months previously. We investigated the potentially damaging practice, a cold call, and no explanation of what this was about and found an incredibly sensitive, thoughtful and supportive process and resources that had been worked on by a group within Health Improvement Scotland (HIS) that included third sector organisations amongst other stakeholders. We raised concerns about how the process had been enacted in this particular health board and finally managed to secure a meeting to note our concerns about the governance around the process. We are highlighting this because with any collection of data there must be a robust approach to protecting the people from whom this data is being gathered. The intentions behind the child death review are welcomed but this must be gathered sensitively. The resources developed are excellent but with no one to ensure they are followed and a health improvement body unable to control what happens locally it is no wonder we have no effective and consistent data collection.

During the meeting with the leads at HIS, PAMIS were told that up until 2 years ago there were no death reviews of a child or young person who had a profound learning disability or for e.g. cerebral

palsy. We realise that because it was expected that they would die prematurely there were no death reviews to ascertain or understand the reasons for the death. This means that for decades there have been no lessons learnt, no calls for further research into treatment and practice, no recognition of how advances in other areas could benefit this group, and worryingly it also meant that this led to the lack of interventions offered and delivered, lack of understanding about effective prevention and treatment and a total lack of planning for a group that could, with the right support, live into adulthood. It has hindered practice, and we would surmise been the cause of many premature deaths. A lack of interest and drive to improve life because of the expectation that people with PMLD will die early anyway has had a profound impact on our organisation and the people we support. PAMIS were shocked that we had not realised this to be the case but equally there are many others who also were in the dark. The revelation leads us very strongly to demand action in fast tracking the decades of inactivity. We therefore would welcome an expansion of the child death review to include all people with PMLD and wider, but please can we start with a group for which there has been so little. We would hope that this will accelerate preventative measures that PAMIS have been promoting for decades like postural care, slowing down body distortion which can lead to respiratory issues and premature death.

However if we are to develop a **Learning from lives and deaths – People with a learning disability and autistic people (LeDeR programme)** we need to ensure it does lead to improvement, that lessons are learnt, that research comes from the findings, that families are included in the investigations in a sensitive and compassionate way but are also seen as part of the in team and enabled to provide insights and expert opinion. And that they are part of the conclusions and recommendations going ahead. This will ensure there is accountability within the programme. Family carers are committed to seeing improvements through, they persevere where others give up, they believe in legacy as a way to manage the grief and this could make the difference to the lives of others and the success of the programme.

PAMIS also consider that the data gathered from the Annual Health checks could also feed into the programme. We recognise that there will be a cost attached to this and we are unclear about the level of resource available within the Bill to develop it. PAMIS suggest that the SLDO is involved in any aspect as their expertise in not only interrogating data, their commitment to making a difference and looking at stark health inequalities but also their passion and track record in involving people with a learning disability and family carers will be very valuable in either expanding the current review process in Scotland of children and young people or developing a Scottish LeDeR.

Q2. Which of these proposals do you not agree with? please tell us why?

Proposal 1: Developing a commission(er) with responsibility for data collation.

The key to better data collection and reporting to enable a far greater understanding of the needs and requirements of people with PMLD and building a robust PMLD specific evidence base lies in collecting more relevant data at an appropriate level of detail. Resources would be better utilised on achieving this goal alongside creating mechanisms for enhancing existing data collections as opposed to creating a specific commissioner role with responsibility for data collation. Currently, the Scottish Government's Chief Statistician is responsible for overseeing adherence to code of practice for statistics as well as setting a standard for statistical classification, methods, and reporting. How would the proposed new commissioner interact in? this role and is it advisable to move responsibility out with the Scottish Government? PAMIS would like to see priority given to strengthening current data collections. At present, policy and provision of services are crudely informed by very limited data which is available but not fit for purpose. Any data improvement programme needs to tighten existing definitions and ensure a much higher level of consistency across data collections. This would make it much easier to connect data together e.g. link the data from different surveys including whole population surveys such as Office of National Statistics Census and to draw out the insights which would inform good policy making. Improvements can be made through a more focussed data improvement programme activity using current structures as opposed to waiting for a new commissioner role.

Q3. Is there anything else that we should consider which is relevant to this topic?

We consider that data that specifically identifies individuals with PMLD is required for appropriate planning.

Families have suggested the creation of a PMLD Index providing data on the complexity and multiple long-term conditions to facilitate a proactive understanding of the reasonable adjustments required to access health care and for better targeting of interventions. The current Key Information Summary (KIS) of a patient's 'needs' that some GPs may keep on record might only amount to a paragraph and not set out the complexity of support, protection, and interventions that people with PMLD require for their health care. The creation of an electronic healthcare "index" (or digital "flagging" system) could be used alongside other approaches to identify and understand patients' complexity, multiple long-

term conditions, low resilience, functional loss, dependence on care, etc. more easily This system could potentially speed up the process of identification of individuals' needs and recognise more effectively when and how medical interventions might be needed, thereby resulting in identifying:

- when treatment may be required
- reducing unnecessary hospital admissions
- improving quality of life for individuals with PMLD
- avoiding pain and suffering
- reducing avoidable deaths

A digital system would allow proactive understanding of the reasonable adjustments required to access health care and for better targeting of interventions. Creating an electronic system would provide a level of advocacy for health care that currently doesn't exist, but which is desperately needed both in terms of benefit for patients and to help health professionals plan support. Cost savings would be achieved in the longer term through improved support and prevention of illness and emergency care.

Section 5: Independent Advocacy

Proposal 1: Strengthen and improve access to existing advocacy provisions.

Proposal 2: Improve our Understanding of Independent Advocacy

Q1. Which of these proposals do you agree with (if any), please tell us why?

Proposal 1: Strengthen and improve access to existing advocacy provisions.

PAMIS agree that there needs to be further work to ensure that independent advocacy is understood and supported appropriately. We are concerned that currently this is not the case and that for people with a profound learning and multiple disabilities where the advocate is not skilled in working and understanding their complex needs inappropriate conclusions are drawn. We would strongly recommend appropriate training in working with people with PMLD and that this should be a specialist area of practice. We know that some local authorities want to have generic advocacy services with no understanding of the complexities in supporting someone with PMLD. We believe this is wholly inappropriate and will lead to further barriers in accessing their human rights.

A significant example recently is when a local council had decided a young person with PMLD should be accommodated in a care home for older people. They engaged an advocate who after one very short visit, having never met the person before, fed back that the person with PMLD had agreed and wanted to live in the care home. There was no visit to the home, no informed decision process and as the person had PMLD there was no chance that they had understood what they were agreeing to. This was wrong on so many levels and not least because the advocate appeared unaware of how inappropriate the accommodation option was for a young person.

PAMIS supports the opportunity to include independent advocacy in the LDAN Bill as opposed to it placed within current Mental Health legislation. PAMIS supports and welcomes the opportunity to improve access to independent advocacy should people choose to engage with advocacy services however the current services are overstretched and as a result do not have the time to dedicate to undertaking the training required to be able to support people with PMLD.

Proposal 2: Improve our Understanding of Independent Advocacy

PAMIS would support the inclusion in the LDAN bill of fully trained advocates for people with PMLD across all aspects of their lives and disagree that the right to advocacy is reserved for only the areas mentioned in proposal two. What is proposed in this section of the bill is not robust enough to suit the diversity of the communities that may require access to independent advocacy. Again, the emphasis on access to adequate and specialist training and support cannot be emphasised strongly enough as without the knowledge and understanding of PMLD and the length of time it takes to get to know and understand how someone with PMLD communicates access to independent advocacy will only add to the already difficult lives of people with PMLD and their families. PAMIS does not agree that access to independent advocacy is restricted to what is being proposed in proposal 2 as it is not robust enough and there needs to be further consideration of the provision of advocacy for anyone who wants it in all aspects of their lives and across their lifespan.

Q2. Which of these proposals do you not agree with (if any), please tell us why?

n/a

Q3. Is there anything else that we should consider which is relevant to this topic?

In order to effectively support and advocate for a person with PMLD the advocate would require to have a specialist knowledge of the complex needs, the way the person communicates, as well as understanding what the aspiration and interests of the person with PMLD are. They would need to have a range of skills that would support their engagement with the person, and they would need to spend time getting to know the individual and developing a relationship.

Families also need support in accessing their rights and in supporting the rights of their loved one. PAMIS provides family support to those caring for a person with PMLD. This is not an advocacy service but ensures that families feel supported and empowered especially at times of conflict with services and public bodies. PAMIS have supported families with training in empowering conversations so that they are able to advocate for themselves and their loved one. We believe this approach should also be considered within this section. Family carers remain the strongest advocates for people with PMLD but as family carers age, it would be advantageous to have access to suitably trained advocates who could work in partnership with families and the PAMIS Family Support Services to ensure that people with PMLD have full access to their rights that would enable them to live a full and

rewarding life where their voices are heard and their rights upheld. This section of the bill is not as strong as other sections and as such is not as robust in its outline of the opportunities that independent advocacy could offer across the lifespan of people with PMLD and their families. Siblings of people with PMLD could also benefit from the support of independent advocacy as their voices are often the silent ones who are forgotten about and there are aspects of their lives that would be significantly improved if they had access to independent advocacy. For example, they often suffer from anxiety, bullying, isolation, and loneliness because of the unspoken pressures they may have because of having a sibling with PMLD. They would benefit from independent advocacy, particularly during the teen years and knowing their rights when making further education choices. Advocacy should be available for them should they choose to engage with it.

Part 3 - Specific Themes

Section 1: Health and Wellbeing

Q1. Which of these proposals do you agree with (if any), please tell us why?

We agree in principle with all the proposals but from the outset want there to be an acknowledgement and naming of the reasons that people with profound learning and multiple disabilities (PMLD) have poorer outcomes than not only the general population but also within other groups of people with a learning disability. This group of people are “not expected to live” and therefore healthcare is delivered with this prior assumption. Investigations are not undertaken, treatment is withheld or not introduced, and assumptions are made by a medical workforce who were educated to expect someone with PMLD will die. Until 2 years ago because of this assumption of a child or young person dying of a profound learning disability or of cerebral palsy, there were no death reviews of this group. There were no lessons learnt, no calls for further research into treatment and practice, and this led to the lack of interventions offered and delivered, lack of understanding about effective prevention and treatment and a total lack of planning for a group that could, with the right support, live into adulthood. In October 2021 the Scottish Government introduced the Child Death Review Process and the National Hub for reviewing and learning from the deaths of children and young people was established - <https://www.healthcareimprovementscotland.scot/inspections-reviews-and-regulation/national-hub-for-reviewing-and-learning-from-the-deaths-of-children-and-young-people/>

For anything to effectively change in the health and wellbeing of people with PMLD, the narrative going forward must change from an expectation of death to an ***Expectation of life.***

Families have shared with us over the last 32 years that the repeated messages they are given is of their child/adult child not being well enough to survive and/or not being expected to live. This mainly comes at the time of diagnosis and hospital admissions. Weight is placed on the difficulties experienced by the individual, and the joy, happiness, love and laughter that they share with their family is very rarely considered. The lives of people with PMLD are often undervalued, with families being told to take their child/adult home and love them as they won't survive for long. Healthcare practitioners are guilty of not considering quality of life from the person with PMLDs perspective, forgetting that someone with PMLD has a different starting point from many of us – often being born

with limited vision, limited mobility, seizure activity, developing health concerns at an early age and being incredibly resilient in being able to live their lives with joy despite these deficits or difficulties.

PAMIS believe that unless this fundamental shift in narrative is set across the whole of this consultation but particularly within the context of health and wellbeing, there will be no change in the outcomes for this group. And we know that better health care interventions can enable people to live well with PMLD. Please see parent Kate Jordan's interview with STV news: [Postural Care | PAMIS¹⁰](#)

This shift in narrative needs to be highlighted within each of the health and wellbeing proposals with supporting statements highlighting how people with PMLD will specifically be supported to live healthy, valued, and inclusive lives.

At the end of this section, we also have a further proposal to support the decades of no progress in advancing the care of people with PMLD.

Proposal 1: Neurodivergent and Learning Disabilities strategies

PAMIS agree with the themes for the overarching strategies but want to see specific account taken of people with PMLD in each of these. We want there to be clear and specific statements about the expectation that people with PMLD will live a valued and healthy and inclusive life. We want there to be clear statements about how locally and nationally this will be supported.

PAMIS also highlight below specific themes that need to be addressed within local and national strategies in order to appropriately support people with PMLD to have better outcomes.

1. **Acute Hospital Pathways** – many aspects of accessing acute care are difficult for people with PMLD and the families who care for them. Attending hospital in an emergency is often the last resort for carers who will persevere in the care delivered at home until healthcare intervention is needed to keep the person alive. It is often the last resort as there is a fear of hospitalization of people with PMLD – will the person be cared for, valued, treated as any other would or is there an underlying expectation that the person will die. Family carers are often excluded from conversations in hospital and feel that they are being seen as a nuisance if they stay to provide the needed 24/7 bedside care. Getting the right bedside care, especially if there are paid

¹⁰ Kara "wouldn't be here today" without postural care treatment, <https://news.stv.tv/scotland/kara-wouldnt-be-here-today-without-postural-care-treatment?top>

carers involved as part of the care team, can be difficult and not having anyone by the bedside can lead to lack of personal care, lack of recognition of seizure activity, postural care, suctioning or communication needs. It is often unsafe for people with PMLD to not have someone at their bedside. We know that people with LD are dying prematurely, many of these deaths happening in hospital admissions. Family carers have also expressed the need to have staff in acute settings knowledgeable in postural care and be able to offer postural care support in ICU, Paediatric wards and when people with PMLD are admitted to hospital.

Acknowledging the myriad of issues with the acute hospital pathway for people with PMLD within local and national strategies, and the accountability of those working within these bodies to deliver information, education and support required to healthcare practitioners at all levels is essential.

PAMIS have been inspired and supportive of the huge amount of work that some of the family carers have been taking forward and we share this below as a model to support HSCPs to develop inclusive and effective strategies, if only they would work with all the team of experts, family carers included.

“Health problems loom large for PMLD families and for many the fear of an A&E emergency or a hospital admission are ever present. For me, fear is waking up every morning with an ever-present anxiety, wondering if this will be another day when I will get a phone call to say that a seizure has thrown Lauren against a wall, and she has to go to A&E urgently. This perpetual worry has been made so much worse by the knowledge that until very recently (and only after 5 years of vigorous campaigning) Social Work would not fund her care staff to support her, in hospital. The anxieties of families and the wellbeing of people with PMLD could be resolved if only there were clear hospital pathways that really put the person with the disability at the heart of the planning process rather than the bureaucratic and financial considerations of the organisation itself. This could be achieved so easily if only the NHS and the HSCP would talk to each other and to families.

I’ve spent more than 5 years trying to persuade Fife HSCP and NHS Fife that Lauren should be funded to be supported by her paid carers if she had to be admitted to hospital. It seemed such a simple thing really. She needs one to one support in her daily life so why wouldn’t she need at least the same level of support in hospital when she is ill or injured? It turned out to be not so simple at all and it’s been an arduous and distressing battle of attrition to persuade the HSCP, the NHS and the Ombudsman of the need for reasonable adjustment to be made. We have eventually made some

progress and Lauren will now receive her care support in hospital but the position for everyone else in similar circumstances remains unresolved and a work in progress.

So many of the challenges facing PMLD families could be resolved if there were clear hospital pathways whether for outpatients, A&E or planned or unplanned hospital admissions. Might it be possible that the high mortality rate for people with learning disabilities is the lack of clarity around how to access the right services at the right time?

Here are a few changes that could make an enormous difference:

- *Clear strategies and processes to help people with PMLD access hospital services.*
- *They should be drawn up jointly by the HSCP and the NHS*
- *They should consult with families, care providers and other interested parties.*
- *The person with the disability should be at the heart of the planning process.*
- *People with PMLD should be supported in a hospital setting by those who know and understand them, whether paid or unpaid.*
- *NHS staff should receive mandatory and meaningful training on learning disability.*
- *LD/L nurses should have expanded roles, responsibilities, and recognition.*
- *There should be greater focus on the use of hospital passports, including digital passports.*
- *It should be easier to access necessary information.*

In other words, people with PMLD should have the same rights as everyone else with reasonable adjustments being considered and anticipated to ensure that is the case."

2. Diagnostic overshadowing –

As highlighted in our introduction to this section one of the biggest barriers to people with PMLD accessing services and interventions that prevent illness and improve overall health and wellbeing is diagnostic overshadowing. We highlighted the death reviews with cause of death being cerebral palsy, this lack of interest in the underlying causes is terrifying.

"One of my greatest fears is diagnostic overshadowing. I continually worry about what will happen to my son when I and his dad are no longer there to look after him. Without health care processes in place to support him, the behaviour he displays when he's unwell may well be put down to his autism and PMLD diagnosis. As his parents and carers, I constantly have to bang on doors for help when my son is unwell. I don't think others would do the same for him."

PAMIS recognise that the other proposal within this section will support our concerns, but the issue requires to be named within local and national strategies along with [plans to resolve the issue.

3. **Postural care** – The management of posture and positioning is integral to health and wellbeing of people living with PMLD. The failure to appropriately support posture and positioning through postural care can lead to a range of health concerns including breakdown of skin integrity, unsafe swallow, body distortion and deformity, pain and discomfort, difficulties with eating, drinking, and breathing, respiratory issues and premature death. The Scottish postural care strategy [Your Posture Matters](#)¹¹ highlights the necessity for postural care to be everyone’s business. Everyone supporting someone at risk of postural distortion needs to be able to provide the best care to achieve the best body shape possible. The lack of recognition of the impact of not supporting someone’s distorted posture leads to avoidable deterioration and death in acute hospital stays.

Story 1a – carer’s experience of a hospital admission with no recognition by staff of postural care [MM hospital experience \(postural care\) edited short \(vimeo.com\)](#)

Family carers supporting people with PMLD have been at the heart of an increase in knowledge and protection of body shape across Scotland, of individuals at risk of body distortion and all the risks that can come with changes in body shape. Family carers were fully involved in the creation of the Postural Care Strategy for Scotland – Your Posture Matters June 2021, highlighting the importance of family carers and people at risk of body shape changes being fully informed of the risks and given training in how to minimise them from the time of diagnosis. It is imperative that national and local strategies supporting people with learning disabilities and neurodivergent people must highlight how they will support and implement the national postural care strategy – “Your Posture Matters” namely training of health and social care staff as well as family carers in 24-hour postural care, provision of appropriate equipment and regular reassessments. The LDAN Strategy needs to emphasise the importance of postural care training from the time of diagnosis, for family carers and those with neurodiversity who have risk of body shape issues, and the importance of postural care education to health and social care practitioners across Scotland. National and local strategies could build in accountability for public bodies to consider what they are doing to promote postural care of people living with learning disabilities and neurodivergent people who also have limitations on their mobility, such as the importance of including carers in conversation about care delivery.

¹¹ *Your posture matters – a strategic approach to taking care of it together*, NHS Education for Scotland, Edinburgh, 2021. pg. 33

4. Impact of the health and wellbeing on family carers – post covid, the impact of caring for people with PMLD is having a significant impact on the health and wellbeing of family carers. Carers Scotland [State of Caring](#)¹² survey highlights that 31% of surveyed carers caring for more than 50 hours a week reported their mental health as bad or very bad with 73% of those carers continuing to provide care ‘despite feeling they are at breaking point’. Most people with PMLD require their carers to care for them 24/7, and this has intensified over the last few years as budgets have been reduced and services have closed. The physical impact of caring has increased too with many of our families telling us they have pain related to physically managing the person they care. People with PMLD are often not able to stand or move around on their own requiring someone to physically change clothes, incontinence pads, transfer from one piece of equipment to another, manage the person’s wheelchair into a vehicle, push their wheelchair out and about – all of these incredibly physical tasks being repeated multiple times during the day. The national and local strategies need to acknowledge this intense caring role and ensure family carers are supported appropriately.

5. Mental wellbeing for people with PMLD - PAMIS are concerned that the mental health issues faced by children, young people and adults with PMLD are frequently overlooked and rarely treated. We know that the pandemic had an adverse impact on the mental wellbeing of this group but there has been very little input from mental health services to address this. We want the needs of this group of children and adults to be named specifically within strategies locally and nationally. We note the research that Professor Jahoda et al¹³ is doing in supporting people with PMLD who are depressed/have low mood and hope that research findings will be implemented in practice. We also believe that there should be a development in supporting people with PMLD who have suffered trauma, particularly in relation to abuse. Currently they receive no support post events and PAMIS want this to be a priority within local and national strategies.

Finally, within any strategy there should be involvement of family carers in ensuring that strategies are enacted and evaluated. We recommend that family carers are involved in the support and supervision of senior health and social care staff. We would recommend the use of the publication “*The Ryan Harper Legacy - ‘a day in the life of... ‘experience influencing allied health professions future practice’*”

¹² *State of Caring 2023 – the impact of caring on health*, Carers UK, London, November 2023.

¹³ *Behavioural activation for depressive symptoms in adults with severe to profound intellectual disabilities: modelling and initial feasibility study*. *Journal of Applied Research in Intellectual Disabilities*, 37(2), e13197. (doi: [10.1111/jar.13197](https://doi.org/10.1111/jar.13197)) (PMID:[38356379](https://pubmed.ncbi.nlm.nih.gov/38356379/))

¹⁴as a framework to support this. Family carers are invested in ensuring that plans are fulfilled and remain committed to improvements because they care passionately about their relative.

Proposal 2: Mandatory training for health and social care workforce

PAMIS agree with the proposal for mandatory training however we believe that there should be very specific training and development to support a greater understanding of people with PMLD.

The complex healthcare of people with PMLD needs to be understood by those working with them and PAMIS believe that many of the concerns mentioned within our response to proposal 1 could be supported by mandatory education model for all health and social care practitioners and enable them to work alongside people with PMLD and their families.

Families of people with PMLD describe how often it is the care and decision making made by doctors and consultants that leads to difficult outcomes for people with PMLD (as mentioned in our introduction). The change of the narrative to an expectation of living must be a basis for awareness training. Understanding about the quality of life that people have through the eyes of families and others who value them will ensure that they do not suffer health and medical discrimination.

PAMIS have for many years been involved in supporting health and social care practitioners to develop an awareness and understanding of the lives of people with PMLD and their family carers. We would support experiential learning, spending time with people with PMLD and their families to gain real insights into the positive lives they can have as well as the complex caring role. Practice placements for undergraduate practitioners are effective and we have also supported the Ryan Harper Legacy – a day in the life of experience which had quite dramatic impacts on both undergraduate students and with newly qualified staff. This resource was co-designed with family carers and delivered by them.

The impact of a placement in changing attitudes towards this group is huge. One student, who had questioned the quality of life of a person with PMLD based on his academic research into the medical literature, surmised by the end of the placement that if, as a clinician, he only looked at the medical quantitative data about the life and medical outcomes of someone with PMLD and didn't take the time to look at all the qualitative data from seeing the person themselves in different situations, looking through their digital passport and spending time with their expert family carers, then he would make incorrect clinical decisions. He realised that the medical knowledge was only a part of the picture and indeed could portray the wrong image. We realised that if he hadn't had a placement with

¹⁴ *The Ryan Harper Legacy: 'A Day in the life of...' experiencing influencing allied health professions future practice.* Edinburgh: NHS Education for Scotland. 2012.
pg. 35

us, he would have been the healthcare practitioner that would have refused treatment or not even assessed the person because the assumed quality of life was so poor.

PAMIS also believes that there should be mandatory training for all health and social care practitioners on:

Postural Care – Postural care is not intuitive, people need to be educated to understand that body shape distortion is not an inevitability and what can be done to stop, maintain or minimise distortion. Informed level digital postural care education is hosted on NHS Education for Scotland’s digital platform, Turas Learn¹⁵ and open to all health and social care staff but this education is not mandatory. PAMIS and some NHS Boards deliver more in-depth postural care education sessions to carers and the health and social care workforce but again, this is not mandatory. PAMIS family carers have been trained to be co trainers in postural care, alongside practitioners.

Family carers and professionals who have attended PAMIS training in postural care have stated that it was very important to hear the lived experience and postural care stories of the family carer trainers.

It can be difficult for people to commit to this education as there’s a general lack of understanding around postural care – if this topic was included amongst the mandatory training topics for health and social care staff it has the potential to create a workforce who can contribute to the sustained and healthy lives of people living with learning disabilities and neurodivergence who have limited or restricted movement. This education needs to be delivered as a stand-alone piece of learning but linked to an understanding of a person with PMLD.

Story 2a – the benefit of postural care education

[5: Postural Care - Sharing Knowledge \(vimeo.com\)](#) ¹⁶

PAMIS also considers it essential that anyone considering becoming a health or social care practitioner should gain positive experience of the lives of people with a disability and in their sixth year spend time with people or organisations that will support them to develop the skills, knowledge and attitudes required to be a part of the caring workforce.

¹⁵ *Your posture matters – a strategic approach to taking care of it together*, NHS Education for Scotland, Edinburgh, 2021.

¹⁶ *Postural Care – Sharing Knowledge*, PAMIS Learning, 2020 <https://vimeo.com/298401699>

Proposal 3: Inclusive communications and accessibility

PAMIS welcomes any improvement in communication and accessibility. We believe that for someone with PMLD staff should ask about whether someone has a digital passport. The PAMIS digital passport holds the communication and accessibility needs of someone with PMLD.

See the recommendations within the Seen – Heard – Included DCYPAG Report 2023¹⁷

[DCYPAG report 2023 WEB updated.pdf \(alliance-scotland.org.uk\)](#)

Proposal 4: Patient passports

It is so important that Family Carers and paid carers of people with PMLD are recognised for the information they can share about the person they care for when the individual with PMLD must go into acute services. This does not always happen, and they can be made to feel as if they are interfering, which can put the child or adult with PMLD at risk due to the lack of knowledge of PMLD and the individual, by the medical staff.

PAMIS Digital Passports can break down this barrier through holding the vital information required by the medical staff about the individual with PMLD. This resource may contain snippets of film, written reports from practitioners or information shared by the family and friends. The Passport can hold documents about the individual's postural care, how they communicate, nutrition, epilepsy and other important information. Importantly Digital Passports can be kept up to date with important information and support their safety.

Quote: We could place a duty on Health Boards, HSCPs and Local Authorities to ensure that a person's "passport" is able to follow them through whichever care pathways they are accessing, such as a hospital or care home admission, and that these passports include important information about their needs and preferences, including how to communicate with them in an accessible way. This could be similar to Advance Statements^[145] that can be used by people with mental health conditions, or it could be based on PAMIS's Digital Passports.^[146]

Passports like these help medical professionals to know how best to support people, their preferred treatments or communication styles, and can reduce barriers and frustration when people have to

¹⁷ *Seen, Heard, Included - Meaningful engagement with disabled children and young people with complex needs and their families*, The Health and Social Care Alliance Scotland, August 2023
pg. 37

repeatedly restate their needs. There is currently no statutory duty placed on patient passports and, although they are encouraged as best practice, implementation is inconsistent.

PAMIS advocate for the use of the PAMIS Digital Passport to support the voices of people who have profound learning disabilities, their families, carers and indeed anyone who would benefit from support with communication. The PAMIS Digital Passport is owned by the individual. They were, uniquely developed by people who have profound learning disabilities and their families over 15 years ago and stand as a legacy, offered by people with profound learning disabilities and their family carers to anyone who needs support with communication. PAMIS Digital Passports are in use across multiple areas supporting individuals' linguistic rights, inclusive communication, complex care, trauma informed practice, human rights, and self-advocacy. They are acknowledged as a gold standard within digital innovation, health and social care.

PAMIS support the proposal to use patient passports across Health Boards, HSCPs, Local Authorities and services working with people who have a profound learning disability. Additionally, we advocate for the use of Digital Passports that use video, audio, and photographs to unambiguously support the needs of the passport owner in a way that is accessible and easily shared.

PAMIS support a duty upon HSCPs, Local Authorities, and NHS Boards to proactively facilitate the means of use of person owned communication documents such as Advance Statements, Hospital Passports and Digital Passports within services.

PAMIS support the principal that the ability to maintain communication skills is a human right, and that people who are assessed as having a communication need and who use communication **equipment** that they are familiar with must be able to seamlessly carry their communication equipment through all transitions across the lifespan.

The PAMIS passport provides a voice for people with PMLD. It enables and supports them to have control over their lives and through ownership of their digital passport they can actively contribute and make a valuable active contribution to how they live their lives. Having a PAMIS digital passport should also be considered as a training tool in local authority commissioning teams to raise awareness of the lives of the people they are assessing.

Proposal 5: Annual health checks

PAMIS believes that annual health checks are a vital part of the redress regarding health inequalities but require a skilled workforce who understand the complexity of people with PMLD. We believe that learning disability nurses should be core to this workforce but that their training requires to have more emphasis on the care and support for people with PMLD.

People with PMLD require health risk assessments to help develop resilience and better manage their overall health care. Health services are legally required to make reasonable adjustments to ensure people with learning disabilities can lead longer and healthier lives. Research¹⁸ into the deaths of people with learning disabilities highlights that a lack of reasonable adjustments to facilitate their healthcare is a contributory factor in early death. Highly skilled learning disability nurses can play a significant role in ensuring reasonable adjustment through the creation of health and hospital passports that could be incorporated into the PAMIS digital passport, assessing mental capacity, anticipatory care planning, reducing clinical risks and enhancing patient safety. They can also improve quality of care by challenging poor practice, and by guiding and supporting colleagues. The Royal College of Nursing recently outlined its ongoing commitment to learning disability nursing. In its report, the RCN acknowledged that people with PMLD had among the highest health needs requiring complex integrated support from health and social care services. The absence of clear data of where registered learning disability nurses were currently working, had limited the accurate identification of the skills, knowledge, and competence the workforce requires. Recognising changes needed for improving future LD nursing, the RCN set out its priorities for competency standards; workforce capability; and levels of education and training.

Most people with PMLD are unable to protect their own health. Clinical guidance by the Scottish Government to support patients with a learning disability during the pandemic recognised their higher risk of serious illness. Sadly however, not everyone with PMLD was on the radar of either health or social care as being in the highest risk group, and in need of protection. The recognition of their ‘multiple’ disabilities that should have put them onto the shielding register was also missed and the diagnostic overshadowing played a significant role in this.

People with PMLD usually have limited communication and rely on others to advocate for their health care. Their families and carers often find themselves having to seek support and information for

¹⁸ *Life expectancy and causes of death of people with intellectual disabilities: a systematic review*, O’Leary, L., Hughes-McCormack, L., Cooper, S-A. (2017) *Journal of Applied Research in Intellectual Disabilities*, DOI: [10.1111/jar.12417](https://doi.org/10.1111/jar.12417)
pg. 39

health issues with an investigative and analytical approach. For most families, the pressure of trying to manage health care is overwhelming and crushing.

People with PMLD require pathways of healthcare that include annual health checks. Evidence on the benefits of health checks for people with LD shows that potentially treatable health conditions can be detected. Health checks appear to be cost-effective as early detection and prevention such as immunisations and screening reduces the costs associated with managing chronic conditions. Health checks can also enhance practitioner knowledge, and confidence in assessment of the health needs of people with learning disabilities. A clear focus on both the theory and practice related aspects of working with and meeting the needs of people with LD to access health care, could benefit all undergraduate programmes for health professionals and practitioners.

Many people with PMLD have not received their annual health checks especially those living in supported accommodation. They should have health checks that are appropriate to the needs of people with PMLD by knowledgeable practitioners. Practitioners need to know what the most common health issues that affect people with PMLD such as respiratory issues, digestive issues and epilepsy, and plan the health check accordingly. There is no register of patients that have PMLD in health practices, but the suggested PAMIS PMLD Hub would support the medical practices around the Annual Health Checks.

Family Carers should be able to request how they see a doctor for their family member as there are few adaptations e.g. hoists, changing places toilets etc, in medical centres so a home visit may be necessary.

Any outcomes from a health check must be followed by prompt referral and treatment. Currently we believe that some investigations are not taking place because it is deemed too difficult, too invasive or the issue re expectation of limited life expectancy, and therefore there is not only no diagnosis but no treatment. This must change.

Q2. Which of these proposals do you not agree with (if any), please tell us why?

PAMIS agree with all the proposals but would like to see more information and representation of the health and wellbeing issues that are important to people with PMLD and their families, more robustly included in the bill because:

- The shocking statistics about the health and mortality rates of people with a learning disability in comparison to the general population and this impacts across all ages and affects the health and wellbeing of families.
- Until 2 years ago there were no investigations into the death of a child or young person with PMLD because they were expected to die. This means that essential information about causes and in turn prevention of premature death have been missed. Parents of children, young people and a growing adult population have been frequently told not to expect their child to live and have not had access to the necessary treatment and interventions that would support their loved one's health and wellbeing. The creation of a PMLD hub in every HSCP would fast track the decades of inactivity in terms of treatment and research.
- Families have not been given appropriate information and training to enable them to effectively support their loved one because of this lack of expectancy to live.
- Values have been and continue to be placed on the quality of life of individuals with PMLD and this has influenced treatment and intervention decisions.
- Acute hospital pathways have not enabled a person with PMLD to be supported by the people who know them best. In some cases, people with PMLD have been in unfamiliar, terrifying environments with no one who knows or understands their communication or needs. Being a highly specialist in a medical world is of no use if the person with PMLD cannot take medication or even enter a hospital environment without the right support from their expert carers, both family and paid social care support.
- As people with PMLD transition from a known team of healthcare practitioners into the adult world, families are suddenly thrown into full time appointment keeper roles, many having to give up their jobs to attend the many appointments with a variety of specialists. There is limited specialist experience of a person with PMLD, and quality of life judgements are often made without a full understanding, or valuing, of the life of the person they see before them. Many healthcare practitioners have very little experience or knowledge of the preventative interventions that support this group to live into older age and have been trained to expect a person with PMLD to die prematurely or develop scoliosis which will impact on respiration.
- A recent professional doctorate research (Glover, 2023)¹⁹ highlights that healthcare practitioners do not view family carers as part of the multidisciplinary care team and therefore

¹⁹ Glover, P. D. *et al.* (2022) 'Evaluating collaborative practice within community-based integrated health and social care teams: a systematic review of outcome measurement instruments', *Journal of Interprofessional Care*, 36(3), pp. 458–472. doi: 10.1080/13561820.2021.1902292.

do not recognise their expertise. They override advice and vital information and make decisions which are not fully informed.

- Many practitioners highlight that they do not feel confident in supporting a person with PMLD in acute and primary care.
- Diagnosing and treatment of mental health issues for children, young people, and adults with PMLD remains under resourced, deprioritised, and therefore ignored.
- Postural care can prevent body distortion and premature death but is not understood or supported by many healthcare practitioners. The assumption that someone will die of cerebral palsy overrides the decision to treat them and prevent the scoliosis.
- People with PMLD are being denied investigations and treatments because they are deemed too difficult.
- There is frequent diagnostic overshadowing.
- During the COVID 19 pandemic many children, young people and adults were left with no health interventions, particularly the loss of their Allied Health Professionals (AHPs). This impacted on health and wellbeing of the person with PMLD and their families. Many people with PMLD lost skills, their health has deteriorated, and their body shape has been impacted. In addition, mental wellbeing has been impacted and skills that were being developed regressed with many losing abilities altogether. The UK COVID Research²⁰ into the impact of the pandemic on people with a learning disability and those with PMLD, recommended that AHPs should provide an increased service and interventions to redress these declines. Families report this has not yet happened.
- The redeployment of healthcare staff away from children, young people and adults with PMLD further highlighted the lack of value placed on the lives of this group - “abandoned, forgotten, invisible”.
- Health transitions for people with PMLD are complex and stressful. The Michael Brown et al ²¹research into these transitions (<https://www.sldo.ac.uk/media/1930/full-report-final.pdf>) suggests a learning disability nurse should be appointed for every child to support the transition and ensure effective interventions are coordinated within adult services.

²⁰ Flynn, S, Hatton, C, Hastings, RP, Hayden, N, Caton, S, Heslop, P, Jahod, A, Todd, S, Oloidi E, Beyer, S, Mulhall, P and Taggart, L (early view) *Access to and use of health and social care services for People with learning disabilities during COVID-19: a longitudinal study*, Tizard Learning Disability Review, 2022.

²¹ Brown, M., Chouliara, Z., Higgins, A., MacArthur, J., & Truesdale, M. (2020). Transition from child to adult health services for people with complex learning disabilities: Learning from families and nurses. Final report. Belfast: Queens University, Belfast
pg. 42

Q3. Is there anything else we should consider in relation to health and wellbeing?

1. We suggest that the summary above in question 2 is considered in terms of health and wellbeing of people with PMLD.
2. Most importantly is the change in the narrative about expectations of living - an expectation that a child with PMLD will become a young person who will become an adult and will be properly supported by planning and delivery of appropriate services and interventions to support them to live healthy and valued lives. This needs to underpin all local and national strategies and be explicit in health and social care workforce education both for the current and future workforce.
3. We consider that data that specifically identifies individuals with PMLD is also required for appropriate planning. Families have suggested the creation of a PMLD Index providing data on the complexity and multiple long-term conditions to facilitate a proactive understanding of the reasonable adjustments required to access health care and for better targeting of interventions. The current Key Information Summary (KIS) of a patient's 'needs' that some GPs may keep on record might only amount to a paragraph and not set out the complexity of support, protection, and interventions that people with PMLD require for their health care. The creation of an electronic healthcare "index" (or digital "flagging" system) could be used alongside other approaches to more easily identify and understand patients' complexity, multiple long-term conditions, low resilience, functional loss, dependence on care, etc. A digital system would allow proactive understanding of the reasonable adjustments required to access health care and for better targeting of interventions. Creating an electronic system would provide a level of advocacy for health care that currently doesn't exist, but which is desperately needed both in terms of benefit for patients and to help health professionals plan support. Cost savings would be achieved in the longer term through improved support and prevention of illness and emergency care.
4. Investment in the national postural care strategy – *"Your Posture Matters"* namely training of health and social care staff as well as family carers in 24-hour postural care; provision of appropriate equipment and regular reassessments.
5. An increase in AHP interventions as recommended in the UK COVID Research Scottish policy brief.
6. The introductions of PMLD Hubs in each HSCP - Much expertise and knowledge already exists within the NHS and HSCPs. However, that expertise needs to be channelled and focused. Our view is that many of the poor outcomes for people with PMLD could be resolved by the

introduction of what we call PMLD Hubs and what others have called “*specialist learning disability teams in acute, primary and community care*”. We envisage centres of PMLD excellence in each HSCP where the specialisms relating to PMLD such as nursing, neurology, gastroenterology, dental, orthopaedics, allied health professionals, GP services, social work services, education and many others could coalesce. We would also suggest that this team becomes a birth to death team avoiding the loss of the health expertise as young people transition into adult services. The benefits for the person with PMLD would be the person-centred, anticipatory, holistic care that many organisations aim to provide but so rarely do. The benefits for the professionals would include: the synergies and partnerships resulting from working with and learning from other specialists in the PMLD field; opportunities to share best practice; scope to identify the interrelated and interdependent medical, physical, emotional and behavioural issues relating to the individual with PMLD; training health professionals in PMLD will equip them to deal with wider aspects of patient health care thereby benefitting the wider population; more comprehensive and accessible research opportunities; improved career development; reductions in delayed discharge; the creation of centres of best practice, innovations and service improvement. In additions the skills of the family carers would be shared as co trainers in all aspects of information, that will break down the lack of inclusion and discrimination. People with PMLD will also be vital tutors, enabling people to learn from their lived experience, such as the Ryan Harper experience and coordinated practice placements.

PAMIS with a group of family carers are keen to support the development of the PMLD hub and our suggestion is that this is included in the Bill in terms of modelling the first one with a roll out planned over several years. This would safeguard the health and wellbeing of children, young people and adults with PMLD going forward.

Section 2: Mental Health and Capacity Law

Q1. Do you agree with this approach? Please tell us why.

PAMIS urges the Scottish Government to take both outlined actions together: learning disabilities should be removed from the Mental Health Act, as well to eliminate the term “mental disorder” in all its occurrences within the suite of bills that fall within the remit of the Mental Health Act. The differing opinions of the Rome²² and Scott²³ report highlight the importance of separating action within Mental Health legislation and the Learning Disability, Autism and Neurodivergence legislation, as there is no unified view amongst professionals in how we may be able to accurately reflect and support the views and needs of people with learning disabilities and those with mental health concerns. Whilst the two identifiers may meet in a Venn diagram of a person’s identity, there is no absolute connection which would indicate that these pieces of legislative work must reflect both identities at once, in every instance.

Within the context of the outlined approaches in the consultation, PAMIS would like to see both language changes to offensive terms, and the removal of people with learning disabilities within the umbrella of mental health conditions, in order to take measures to protect people with learning disabilities, particularly those who have PMLD or who may be unable to utilise verbal communication to make their position within the law known to professionals who could make a decision about whether the mental health laws are applicable in a situation.

We agree with the work that is required to implement supported decision making. Currently PAMIS supports families to make applications for guardianship as a means of safeguarding the rights of their relative when they become an adult. This is an expensive and at times stressful process. We would like to explore how Supported Decision Making²⁴ would work for people with PMLD. Family carers must be involved in that process and need to be seen as the enablers of their relative getting access to the best life. We are concerned that there is a lack of understanding about the time it takes to get to know a person with PMLD to effectively support them to make decisions, and that people, practitioners and others, do not value and respect the family carer and their current role in supporting their loved one to make decisions.

²² Rome, Andrew & Evans, Catherine & Webster, Simon. (2019). Final report of Scotland's Independent Review of Learning Disability and Autism in the Mental Health Act.

²³ Scott, John (2022). Scottish Mental Health Law Review – Final Report.

²⁴ *Mental Welfare Commission – Supported decision making a good practice guide*, 2021.

Q3. Is there anything else that we should consider which is relevant to this topic?

Taking actions which reduce the stigma of learning disabilities from an “illness” as the current language applies, may begin to rectify the damaging implications of merging protection with evaluations of capacity for people with PMLD. However, this action alone is not enough, and we are increasingly concerned at the invisibility of people with learning disabilities within a legislative context, particularly for those who need support to make decisions or express their views.

We would like to encourage the Scottish government to review, in line with the LDAN bill’s inception, the impact of this legislation on individuals who are currently supported through Guardianship orders or require supported decision making. Ensuring that the least restrictive option is enacted at a consistent and recordable statutory level will require that people who use nonverbal communication or supported decision making are able to express their views and retain some measure of choice and control within their own lives. An effective approach to this will separate their capacity from mental health, allowing it to stand alone as a part of our national commitment to hearing the voices of every individual, even when they communicate through the support of a guardian or other support measures.

From a practical standpoint too, consideration also must be given to the impact of having PMLD sitting under local mental health strategies. Sitting under mental health strategy effectively excludes people with PMLD from accessing the vital equipment they require for daily living. Equipment for daily living is not even considered under local mental health strategies therefore in a lot of situations it is denied on the grounds it does not fall under this strategy. This leads to unnecessary problems around funding and provision of vital life changing equipment and whose responsibility it is to supply this equipment. People with PMLD are also not considered when it comes to discussions around mental health, and it is wrongly presumed and assumed that they don’t suffer from poor mental health and yet again the local strategies omit to deliver for this group. It is imperative that people with PMLD and their families are considered in any future discussions around capacity and mental health legislation moving forward because currently sitting under mental health causes unnecessary misunderstandings and stress and leaves mental health policies open to misinterpretation locally.

Children, young people and adults with PMLD are seldom seen in mental health services, their mental health issues remain undiagnosed or treated. There are many cases of diagnostic overshadowing and a lack of acknowledgement that people with PMLD may have a mental health issue. This group slip through the net and are not picked up by mental health services and may go onto to develop significant challenges to service providers and families. There are also a number of people with PMLD

who have suffered abuse resulting in serious trauma which also goes untreated. This group of people require access to specialist mental health services and appropriate support and treatment.

Section 3: Social Care

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: Neurodivergent and learning disabilities strategies.

In terms of proposed legislative requirements for local strategies to set out how they commission services and take into account the needs of people with a learning disability and of neurodivergent people in their workforce planning and workforce training as well as inclusive communication and accessibility, PAMIS would suggest that there should be specific detail on this in terms of people with PMLD. Currently there is a lack of knowledge, skills and understanding by commissioning bodies within local authorities about what is required to support people with PMLD and their families. This lack of understanding is often found to be the root cause of many care service providers being awarded contracts to care for very complex people that they do not have the practical knowledge and understanding of the skills required to undertake the support. Often this lack of understanding results in sub-standard care provision and care breakdown which has resulted in admissions to inappropriate care settings such as care homes for the elderly and out of are placements. It is imperative that commissioning bodies are included in any future workforce training. There must be inbuilt accountability for local authorities and organisations who do not undertake and provide the care necessary to provide people with PMLD with support that enables them to have purposeful and meaningful lives as is their right to do so. Wording in national policies and strategies must be clearly laid out in a way that it cannot be misinterpreted or misrepresented at a local level as that is what currently takes place regularly and is another cause of many inappropriate and failed placements.

Local authorities should work alongside organisations who specialise in working with people with PMLD and their family carers, harnessing their knowledge and expertise for their inhouse workforce, alongside supporting families to access inclusive communications which are relevant to providing care to people with PMLD. These organisations can also offer training in a wide range of topics specific to people with PMLD.

We want to see third sector organisations with specific knowledge and experience of PMLD being valued and respected within the Bill and within local strategies as this will enable the unheard voice of people with PMLD and their family carers to be amplified. We want to see the hierarchical power model levelled and people with PMLD, their families and the third sector being equal partners. This approach needs be taken from the start of all future planning – including accessible services, lifelong learning and community planning within local authorities.

The decisions that are currently being made within social care provision for people with PMLD highlight the lack of respect for the expertise and knowledge that family carers have and the huge role they play in the complex lives of their relatives with PMLD. They are subjected to fighting for their loved one to have a life of meaning and purpose, an inclusive life and on top of also caring 24/7 often in inappropriate housing and communities that don't know how to be inclusive. People with PMLD are a further marginalised group within an already marginalised group i.e. the wider learning disability community, but if statutory services were compelled to work collectively with people with PMLD and their families and the organisations that support them, life could be very different.

We believe that local authorities are failing to recognise the complexity of care and interventions required by a person with PMLD and that there is a lack of empathy or understanding about the emotional and physical strain on the family carer of caring 24/7. This frequently leads to ill informed decisions about care packages and SDS budgets awarded. Families have struggled through COVID with a promise that services would resume but are now being judged by the fact that they 'coped', and many current packages are not being adequately resourced. This impacts on the quality of life and the health and wellbeing of both the person with PMLD and their families. When families do complain there is a lack of appropriate forms of redress, the current systems are far too complex and time consuming for carers to pursue.

Currently the ability to have a life of meaning and inclusion is greatly diminished because of the social care workforce crisis and the lack of appropriate lifelong learning opportunities for people with PMLD. There are shortages of social workers to provide assessments and access to budgets at transition and there is a lack of services for young people with PMLD to move on to. Many people with PMLD lost their day opportunities when the pandemic hit and for most the access has either not returned or is greatly reduced. In some areas the pandemic was as excuse to close building-based services. A lack of knowledge about complexity of care has led to these decisions and for a person with PMLD who requires a changing places toilet, a safe space to be when requiring medical interventions, a warm place when not ill enough to stay at home but not well enough to be out in all weathers, and an adapted accessible environment to take part in activities and to meet peers, this has devastating consequences.

Local authorities need to consider the specific needs of people with PMLD within local strategies.

1. **Mandatory training for health and social care workforce**

PAMIS agrees that there should be mandatory training for the health and social care workforce, but we are concerned about how this will be designed and delivered given the diversity of the people that will be within it. We are also very clear that currently there is very little training available to support people in understanding the lives of a person with PMLD and of their family carers. This includes a lack of knowledge about the value of their life, how to involve and include them and how to support their very complex needs. This we believe means that the wrong decisions are made in many areas of health and social care that impact on the lives of this group and their families.

We know that because of this lack of knowledge, skills, and understanding catastrophic decisions are made about care, access to services, design, housing and support. We regularly hear of social work staff making the final decision about equipment, activities or housing when they have no training in the specific health needs of an individual. They override the family carer and healthcare practitioners because they have the budget but not the knowledge of the person with PMLD and how to engage, support and include in an effective and meaningful way. This combined with the lack of expectation to live a full life further exacerbates the issues that people with PMLD and their families face. Therefore, training needs to be on many levels for people with PMLD – training about profound learning disabilities, about multiple complex co-morbidities, about communicating with them, engaging them, building inclusion, providing meaningful opportunities, but also about how to work as a team and with the whole team, family carers included. It also requires staff to learn how to reflect on what they see with all their senses – a skill that can be used in all areas of life.

In practical terms training of care staff supporting people with PMLD needs to be taken forward now. Currently with many staff not being able to access appropriate training it is falling on the family to provide informal training to staff supporting their relative with PMLD. While family carers are experts in the support of their relative, this places an additional burden and stress on the family, who already have a huge care role. It can also then leave the family open to litigation, should there be any issues with the staff support provided – or with the health and wellbeing of an individual support staff member.

Due to the complexities of the support needs of someone with PMLD, a carer is always required to support them in hospital, because hospital staff neither have the resources to provide the level of care required, nor do they have the very specific training, knowledge and expertise needed. This would include a specialist knowledge of postural care issues, as many people with PMLD are unable to reposition themselves in any way, even when they are well and not in hospital. Many people with PMLD have complex eating and drinking protocols. This can include administering all foods, liquids, and even medication via gastrostomy tube. Others may have specialist pureed diets, which can result in frequent choking incidents and aspiration if they do not have the correct support. Some people with PMLD have regular respiratory problems requiring frequent suctioning. Many people with PMLD have epilepsy but may well be hospitalised at times for other reasons. But they would still need continual observation and support as a life-threatening seizure could occur at any time. Most people with PMLD have very little understanding and usually no formal verbal communication, meaning that acute hospital staff may not understand how the person with PMLD is feeling or if they are trying to communicate something. Staff can also have problems trying to communicate with the person with PMLD, e.g. with regards to procedures that they are required to carry out. Many of the areas highlighted could also be true within other areas of health and social care. There is a need therefore not for the acute/primary care practitioner to have all the skills to manage this complex care, but to have the knowledge that a person with PMLD will have complex needs and will need a known carer to support them. The training they need is to develop their awareness of the complexity of care, to develop communication and engagement skills, to understand that out with an acute episode people with PMLD do have valued lives; and team working and high level communication skills to enable them to work effectively with family carers, the person themselves and the paid carers that are supporting the person. Most family carers will be the legal welfare guardians if they have an adult relative with PMLD, which means that they have a legal responsibility to ensure that their relative's health, care and well-being needs are always met, health and social care staff need to be aware of this probability and also the implications for their engagement.

Regarding social care staff training, for the reasons listed above, if a staff member is going to be providing support to a person with PMLD, it is essential that any training they receive is targeted to that individual with PMLD. This is the only way that the health and wellbeing of the person with PMLD can be met and sustained. It is essential that anyone paid by public funds e.g. via an SDS budget, must have appropriate access to training that meets the individual needs of the person they care for. This is essential to mitigate any risk to the life of the person with PMLD. Greater investment must be put in place to ensure all training to support people with PMLD is of the highest possible standards.

This would include third sector and private care agency staff, as well as employed and self-employed Personal Assistants (PAs). There also needs to be increased investment and value placed on the role of social care staff and acknowledgement of the skills required to care for people with PMLD.

Enhanced rates of pay are essential for this staff group and should reflect the level of care that staff are needed to provide for people with PMLD, because of the person's very specific care and communication and health needs, as previously mentioned.

Social work staff need to be trained fully in the support of people with PMLD so that they can produce the correct detailed assessment of these needs in order provide an appropriate SDS budget for the person concerned. Without the appropriate level of SDS budget, the support and wellbeing needs of the person with PMLD cannot be met. If this happens the burden of care for the person with PMLD almost always falls on the family carers, whose own health and wellbeing can then be hugely affected. Currently PAMIS would suggest that social work staff do not have the necessary knowledge and skill to deliver these assessments to people with PMLD accurately. However skilled social workers will ensure that the whole team contributes to the assessment and that value is placed on the contributions made by others, including family carers as experts in the care of their relative. Unfortunately, this does not always happen and is one of the most frequent reasons for referrals to our family support service, inappropriate assessments that then do not provide adequate support.

There needs to be an investment in appropriate training that will consider both physical, social, and emotional health of people with PMLD. It is essential to ensure people with PMLD get the support they need – to give them the best quality of life and to keep them safe. Mandatory training would not address all of these requirements and runs the risk of being a tick box exercise that does not necessarily fit with the desire to have a GIRFEC²⁵ approach to care. Creative methods of how to engage with and include people with PMLD should also be considered in any training programme.

PAMIS recommend opportunities for learning to be experiential spending time with people with PMLD and their families to gain real insights into the positive lives they can have as well as the complex caring role. Our undergraduate practice placement model for health and social care students has successfully supported students to develop knowledge and skills and enhanced empathy with the role of the family carers. Students have worked alongside families, have learnt from them and the person with PMLD, have encountered issues that have taken a whole team approach to solve, and

²⁵ Getting it right for every child, Scottish Government, <https://www.gov.scot/policies/girfec/>

this has also enhanced their knowledge and respect for the wider health and social care team. We have seen students develop their skills in team working, enhance their communication and interpersonal skills, find creative skills they didn't know they had and change attitudes about inclusion, accessibility, and the value of a life of a person with PMLD. There is no substitute for experiential training methodology that includes time for reflection and supervision.

We have also supported the Ryan Harper Legacy²⁶ – a day in the life of experience which had quite dramatic impacts on both undergraduate students and with newly qualified staff. This resource was co-designed with family carers and delivered by them and offered an insight in the life of a person with PMLD and their family. Dates were made for an evening visit, a time during the day at day services, school or an appointment and an early morning visit. The learning from both the person taking part was significant but also it enhanced the knowledge of the families about the profession the student came from and in turn enhanced the relationship with services and practitioners. This model of workforce development could be used in many areas and families have frequently suggested that senior management would benefit hugely from this.

PAMIS also considers it essential that anyone considering becoming a health or social care practitioner should gain positive experience of the lives of people with a disability and in their sixth year spend time with people or organisations that will support them to develop the skills, knowledge and attitudes required to be a part of the caring workforce.

2. Alternative communication and easy read documents

People with PMLD usually present with a very limited learning capacity (functioning at around the age of 2 years, even if they are an adult) so no written form of information would be accessible to them. People with PMLD are reliant on their family carers to interpret at an appropriate level all communication and information they require. If the person lives in supported accommodation this role would be provided by their staff team and still often involves the family carer.

However, video and audio explanations/footage, as well as easy read materials, can be a useful alternative means of communication for family carers. Most family carers have a huge care role, making life already stressful and challenging for them, so anything that can ease this situation will be extremely helpful.

Online or phone appointments should also be offered to families with relatives with PMLD, as this can be extremely helpful for them in managing their care role. This is particularly appropriate because of the volume of appointments required for a person with PMLD - and because of the practical difficulties of getting their relative out and about, particularly if they are unwell. Having different options to choose from can help makes families' lives easier to manage.

Specific services who have knowledge and expertise about PMLD should be commissioned to support this group through the complicated complaints system. Because most complaints would usually be complex, and therefore incredibly stressful for the families to deal with, these support services are essential to ensure services are meeting the needs of people with PMLD appropriately and safely.

People with PMLD can be supported to have a voice through the use of their Digital Passport if they have one. The Digital Passport supports and enables people with PMLD to be more fully involved in any communication about their lives, it helps them to be included and enables and supports them to participate in discussion about them. [PAMIS Digital Passports | PAMIS](#)

PAMIS also recommend that more resource is put into supporting people with PMLD to engage with services and to understand the services being offered or procedures being required. The PAMIS library of multisensory stories including the sensitive stories is one approach that could be used. We also highlight the engagement tool [I Can If You Can.](#)

Q2. Which of these proposals do you not agree with? please tell us why?

PAMIS does not agree that Mandatory Training on its own can provide what is required for the approach that the Bill proposes. Mandatory training runs the risk of becoming a blanket approach and that is at odds with the proposal of a GIRFEC and person-centred method of support.

Q3. Is there anything else that we should consider which is relevant to this topic?

PAMIS would like to see specific reference to people with profound learning and multiple disabilities (PMLD) throughout this Bill. Their complexity needs to be understood and planned for, but they also need to be seen as individuals with the same rights as the rest of society. They are entitled to - and deserve - a full meaningful life, with access to lifelong learning, stimulating and motivating activities - and support from trained specialist, competent staff who can meet their support needs as well as their health needs. They can live a very purposeful and meaningful life if we can get it right for them.

In summary PAMIS would like to see:

- The involvement of family carers of a person with PMLD and PAMIS in defining the knowledge, skills and values required to work with children, young people, and adults with PMLD. They should then be involved in the codesign and delivery of training as well as playing an essential role in any evaluation.
- The involvement of family carers in ensuring that strategies are enacted and evaluated. We recommend that family carers are involved in the support and supervision of senior health and social care staff. We would recommend the use of the publication "*The Ryan Harper Legacy - 'a day in the life of... 'experience influencing allied health professions future practice²⁷'*" as a framework to support this.
- Consideration of training the next generation of social care and health workforce prior to joining a preregistration course, mandatory volunteering courses in sixth form prior to being accepted on a health and social care course.
- Commissioning bodies included in any new workplace training.
- Workplace training to be a mandatory requirement enshrined in law with full accountability.
- Any national and local strategies and policies must be unambiguously worded with no scope for misinterpretation at local level.
- Any workplace training to be co-produced in partnership with people with lived experience and their families as well as organisations who specialise in working with people with PMLD thereby sharing knowledge and expertise.
- Increased investment and value placed on the role of social care staff. PAMIS recommend that a priority should be on reviewing the knowledge, skills and values of the workforce caring for people with PMLD and that their salaries should be enhanced to account for the specialist role. This is urgently required.
- Far greater flexibility and scope for providing communications in a range of formats to make life easier for family carers who often struggle to attend appointments or take spontaneous phone call appointments. Consideration of inclusive and accessible formats for people with PMLD recognising the need for expertise and length of time it takes to ensure they are involved and included.
- People with PMLD experience health inequalities which can limit their life expectancy. However, an increase in awareness in the need for quality healthcare combined with appropriate interventions supported by a skilled group of family carers means that there

should be an expectation of people transitioning through life. Therefore, social care planning for a person with PMLD requires to consider the full range of services across their life span.

Section 4: Housing and Independent Living

What do you think?

Currently, people with PMLD face multiple barriers to accessing suitable housing and housing support. The majority are denied a choice about where they live, who they live with and the support they receive. They are often isolated from their local community, unable to exercise their legal right to equal choices and full inclusion and participation in the community. Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD²⁸) states that persons with disabilities should have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement. These rights are currently being denied for the majority of people with PMLD and PAMIS views the LDAN Bill as a crucial opportunity to dramatically improve this situation across Scotland in the coming years. Housing and independent living remain critical human right issues for people with PMLD. Whilst the current Housing to 2040²⁹ vision and route map is welcomed along with the reviewing the Housing of Varying Needs³⁰ and social housing design guidance as well as the creation of a Scottish Accessible Homes Standard which aims to raise the baseline level of accessibility, adaptability and usability of all new homes to meet the needs of different people, PAMIS would like to see specific consideration given within this for people with PMLD who have complex care needs and a much more robust focus on how public authorities' duties around housing and independent living can best be met for people with PMLD.

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: Advice, Advocacy and Guidance

PAMIS strongly agrees that an independent advocacy service specialising in housing support is needed in Scotland and that this should encompass the delivery of specialist services for people with PMLD and their families. PAMIS is regularly asked for advice and support in relation to housing and adaptation issues from the individuals our charity supports, something we have been delivering through our various support services for many years. We have been able to offer an individual and far more personalised approach that takes into consideration all relevant personal circumstances and

²⁸ *Convention on the rights of persons with disabilities*, 2006, <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles>

²⁹ *Housing to 2040*, Scottish Government, Edinburgh, March 2021

³⁰ *Housing of varying needs: a design guide*, Pickles, TSO, 1998.

support needs as well as housing needs. However, in reality the housing needs for people with profound learning and complex physical disabilities are currently not being met. The options for housing for this group are woefully inadequate and place not only the person with PMLD at risk but also the family carers.

PAMIS would like to see the housing adaptation process streamlined so that it is easier for people to navigate and that guidance on this is consistent and more accessible. It is crucial that any advice and advocacy service helps people understand what their human rights are but also that there is a form of accountability to ensure these rights are upheld. PAMIS would urge that more detail is provided on how this service might be funded.

Proposal 2: Neurodivergence and Learning Disabilities Strategies

PAMIS strongly supports the development of local strategies that require local authorities to report on how independent living principles are embedded into assessment and allocations policies. We would specifically want to see a focus on people with PMLD within local housing strategies and that progress is evaluated. By linking into Local Housing Strategies (LHS) more consideration can be given to ensuring the delivery of accessible homes in the right places (see additional information about inclusive communities being vital for people with PMLD below.) Since people with PMLD will frequently require supported living accommodation it is vital that local strategies link with health and social care strategies. It is important that additional funding is released to enable this development.

Proposal 3: Mandatory Training for Housing Professionals

PAMIS considers mandatory training on supporting people with PMLD and their carers for housing professionals including architects and other professions, as well as those working in health and social care as a fundamental and minimum requirement of this Bill proposal. There is currently a huge gap in knowledge amongst housing professionals about the needs and requirements of people with PMLD. Mandatory training has the potential to be transformative but careful consideration given to how this is delivered. PAMIS' learning and development training programmes are all co-produced with family carers to ensure they accurately reflect the support needs, of people with PMLD, but it is also the case that family carers are the absolute experts in how best to support someone with PMLD and it is critical that their voice is heard and understood fully. PAMIS have many years' experience of supporting the next generation of health and social care practitioners through practice placements within the organisation and an opportunity to learn from people with PMLD and their families. This interprofessional approach has been highly successful and is an opportunity to grow a workforce who understand complexity but also have solutions for inclusion. An opportunity to also include housing

professionals in this education model would support collaborative approaches to the current housing issues.

Proposal 4: Data

From PAMIS' point of view, there is currently a need to improve data collection at both a local and national level. Our main cause for concern is the future supply of new specialist housing and the demand for adaptations. Currently there are significant gaps in the data that is available and collected about people with PMLD and without this how can we accurately project and improve the future supply of suitable housing? There needs to be a far more detailed assessment of the housing needs and preferences of people with PMLD to positively address the current barriers to housing.

We also recognize that there has been a lack of expectation that people with PMLD will live into adulthood. This narrative needs to change and preparation for an increased number of children, young people and adults with PMLD who will require specialist adapted housing should be expected. Data about the numbers of children with PMLD needs to be shared so that future planning can take place.

In addition, Housing Needs Demands Assessments which feed into Strategic Housing Investment Plans require more robust data about the requirements of people with PMLD, if they are to provide an evidence base for an increase in the supply of suitable, accessible housing for people with complex needs across Scotland.

Proposal 5: Inclusive Communications

PAMIS' main views on inclusive communications are set out in our response to the overarching theme on this subject and we support the proposal for this in relation to housing specifically.

Q2. Which of these proposals do you not agree with? please tell us why?

N/A

Q3. Is there anything else that we should consider which is relevant to this topic?

PAMIS are concerned that the current proposals still do not address the key and fundamental issues that affect people with PMLD and their carers. During the engagement phase of PAMIS' preparation for responding to this consultation, families told us that it is still too common for the individual with PMLD to be living in institutional settings with no evidence of clinical need resulting in a denial of their basic human rights. They told us that current housing models are unable to deliver a truly person centred, tailored and individual approach to independent living, resulting in a serious lack of meaningful choices and control. Housing for people with PMLD needs to be located with

consideration of nearby services and public transport and planning should consider how the housing fits in with the wider community and local amenities. How inclusive and accessible local communities are goes hand in hand with building more accessible housing. The need for more accessible public spaces and buildings which include appropriate toilet facilities such as Changing Places toilets is key to promoting independence for people with PMLD and their families. There is currently a significant lack of single storey, accessible and suitably adapted housing for people with PMLD as well as lengthy waiting lists for housing adaptations with carers resorting to using shower and bathing facilities in public Changing Places toilets as the facilities in their current home are not appropriate and they are waiting for basic adaptations. People with PMLD would benefit from being prioritised for housing adaptations and more accountability is required to ensure this happens. PAMIS want to see the introduction of a minimum floor size for bedrooms in housing for people with PMLD which also includes the provision of adequate storage. Consideration should be given to the introduction of a target or measure for the number of homes built specifically for those with complex care requirements.

Families must be able to maximise choice and control over where they live and in what type of housing. Young people should be able to exercise full freedom of choice about who they live with and not simply be presented with the sole option of living in a care home. The individual with PMLD must be at the heart of the decision-making process to make sure all housing and accompanying care packages are appropriate, with fully trained social care staff who understand the importance of providing a purposeful and meaningful life for someone with PMLD.

PAMIS would hope that all new housing will be built with accessibility in mind so that people with PMLD can visit friends and family and not worry about whether the door widths are big enough or whether there is level access. Currently we restrict opportunities and inadvertently promote isolation and loneliness by not building for inclusion.

Section 5: Complex Care, Coming Home

What Do You Think?

Should there be a statutory duty upon the relevant public body or bodies (Integration Authority, Health Board, Local Authority) to hold a Dynamic Support Register? (Proposal 1). Please tell us more.

PAMIS agree with proposal 1 that there should be a statutory duty to hold a Dynamic Support Register. We know that currently people with a learning disability and complex care needs are at risk of their support breaking down and do not have adequate plans for the here and now, never mind the future. We also know that this is having a serious impact on both the person and their families and/or those who care for them within services. We are aware of several young people who will end up in an out of area placement because of lack of support, facilities and no planning for their future. We want the dynamic support register to also capture children and young people. This will enable appropriate long-term planning as well as ensuring that families are supported to maintain their caring role. All of this requires to be legislative because currently local authorities and HSCPs are neglecting this group and are not providing adequate support and care. It would also ensure that the reasons for breakdown are examined, and solutions sought. We also know that if children are identified at an early enough stage appropriate interventions and support can be provided which may prevent further challenges and address the underlying causes that then require complex care support. Currently we are aware of several cases where families have no support and no respite from a complex caring role. We know that these families are at breaking point and in some cases at risk of harm but there are no services supporting them and no plans for future provision when they reach adult services.

We recognise the competing demands on HSCPs but for decades people with a learning disability have not been a priority. Labelled as “challenging”, the solution has been to shut them away and there has been no appropriate early intervention to prevent the breakdown of home life. Frequently supported by social care staff who themselves have no support, no supervision and limited training in purposeful and meaningful occupation, support arrangements have broken down. This lack of support and recognition of the need for a highly skilled and supported workforce means that recruitment is impossible in some areas.

These issues and plans to overcome them must be owned by the HSCPs and we feel that the duty to hold a dynamic support register and to provide evidence of planning will support this.

We strongly urge the Scottish Government to extend the reach to include children and young people before they are the next generation of out of area placements. There must however be consequences for not developing these registers as a tool to improve services. Audit of plans and outcomes from these needs to be part of the process and we assume will feed into the national support panel.

Which of the options for the National Support Panel (Proposal 2) do you think has the most benefits? [Option A, Option B, Option C]. Please tell us more.

PAMIS were part of the peer review visits for the NHS Quality Improvement Scotland clinical standards board for Scotland (CSBS) learning disability standards. In the early 2000s PAMIS supported family carers to engage with the peer review alongside people with a learning disability and health and social work practitioners. Each health board in Scotland was visited to review their learning disability services against a set of standards which had been co-produced by people with a learning disability, family carers, practitioners, and academics. This was a gold standard approach and within the suite of Clinical Standards Board for Scotland (CSBS) standards, was one of the most effective review processes. For the reviewing team it was an opportunity to see good practice, share practice from other areas, provide advice, support but also hold to account services that were not meeting the standards. The services were rereviewed a year or so later to check on improvement plans. However, the implementation of plans depended on committed, passionate practitioners and local service managers and in some cases the senior officers from the health and social care Boards didn't get involved. There was no consequence if improvements didn't occur and although an excellent model for sharing practice, peer learning and opportunity to build more effective services, without the law to enforce improvement there was no requirement to do so.

PAMIS believe that option B could replicate the excellence in the peer review process mentioned above but by being required by law to undertake the review and then to make the recommendations happen, HSCPs will have to improve their services and support for people who have been neglected, ignored, locked away and not been able to access a quality life.

PAMIS believe that Scottish Government should build on a model that worked previously (the CSBS learning disability review process), provide the support and training for those participating in the peer review teams and ensure that family carers and people with lived experience are a part of that expert team. We believe that not only will the peer review support the HSCP being visited but it also provides excellent development for those on the panel. With appropriate leadership, training, and support for the team it also enables practice to be shared, relationships to be developed and solutions to be

found to support people with a learning disability and complex care needs to live within their communities.

Careful consideration of what happens when HSCPs do not comply or deliver needs to be articulated. Support to do the right thing should be forefront but not delivering on recommendations must be addressed. We have been here before and this Bill must make the difference.

Are there any other options that you think we should consider?

See above. If the peer review process was also labelled as a continuing professional development opportunity there would be a greater incentive to join this approach.

Section 6: Relationships

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: Access to Independent Advocacy

Right to Advocacy for people with profound learning and multiple disabilities (PMLD)

PAMIS agrees that the voices of people with PMLD have a right to be heard and their needs met. In relation to advocacy for this group, it takes so long to get to know, understand and build trust with someone with PMLD and their families that a specialised Family Support Service like PAMIS is necessary to support the full understanding of the complexities of support required. We are concerned that without specific understanding of this group, misinterpretations of aspirations in relation to valued relationships may occur.

Expectations of this group of people are often underestimated and this impacts on interpretation of decisions especially in terms of relationships. PAMIS believe that a specialist service like PAMIS can offer support across all aspects of the lives of people with PMLD. Advocacy for people with PMLD really must be a partnership with family carers who understand them and an organisation like PAMIS supporting an empowerment model where families are supported with the necessary information, advice, and support to ensure that the voices of their loved one with PMLD is heard. “Traditional” advocacy services are usually not equipped with the specialist knowledge and training in working, supporting and communicating with someone with PMLD, including the knowledge and impact of the complex health care needs of this group.

We are concerned that without the specific understanding, skills, knowledge and time an independent advocacy service will not be able to provide the service required to support people with PMLD in any meaningful way.

Proposal 2: Data

Proposal 2

PAMIS would like to see improved relevant data sharing across and between services and believe this would greatly enhance the transfer of information that will benefit the lives of people with PMLD. Understanding the numbers of people with PMLD, the complexity of their needs but also their aspirations can only support a more inclusive world and enable local strategies and services to be

developed that enable them to be included within their communities. To help navigate the current data sharing process PAMIS use the PAMIS digital passport that belongs to the person. This means that the person can share any aspect of their life with whom they choose. The [PAMIS digital passport](#) supports people with PMLD in several ways. It prevents the constant repetition of aspects of the person's life repeatedly, which can be traumatic for both the person with PMLD and their families. It avoids the complexities of data sharing. It also enables the person with PMLD to have a voice and to highlight aspirations and preferences, to have a personality. It can support others to understand who is important in the person's life and ensure that relationships with friends are maintained. It also provides an opportunity for policy makers to hear from this group and to revisit the responses that have already been made to policy questions without asking again. We share the "[I Can If You Can](#)" toolkit here as a tool to understand what is important to this group of people, much of what is contained in here is applicable to how relationships are made, supported and enabled.

Proposal 3

Inclusive communications

PAMIS would like to see improved inclusive communications with people with PMLD and their families across all sectors of health, social care etc as well as in communities. This will require support and education of a workforce across many sectors and communities. Again, the PAMIS digital passport supports people with PMLD to have a voice. By sharing their passport, the person with PMLD is empowered to communicate their likes, dislikes and to show how they like to be treated as well as providing much needed information around their care and support needs. This is particularly important in the acute hospital setting where they might be unknown to hospital staff. The digital passport is an excellent tool for relationship building in all settings and with everyone involved in the person's life. Understanding the communication of someone with PMLD takes time and requires us to listen with all our senses. We need to develop approaches that support time, evidence-based practice and inclusion of those who know the person best. We are concerned that there are not enough specialist practitioners to support alternative communication to ensure that people with PMLD are heard and included. Please also note our comments above regarding data sharing and the role of the passport and our [I Can If You Can](#)³¹ resource.

In relation to gender-based violence we believe that there is a need to identify people with PMLD explicitly as support for them post abuse is rarely given, numbers are not known, and risks of this occurring are currently not being addressed.

³¹ Part of *Seen, Heard, Included - Meaningful engagement with disabled children and young people with complex needs and their families*, The Health and Social Care Alliance Scotland, August 2023.

Proposal 4

National and Local Strategies

a) PAMIS would welcome A Whole Family Approach adopted across all sectors involved in the lives of people with PMLD and their families. However, we need to be extremely clear about what this means in reality for the families that PAMIS support. Unless families of people with PMLD are specifically mentioned we are deeply concerned that there will be a one size fits all, such as carers centres delivering support that is not tailored to the needs of families with children, young people and adults with PMLD.

Understanding how families can retain relationships with their communities when there are no inclusive facilities such as changing places toilets, and accessible events is a serious gap in the knowledge of many organisations.

PAMIS would also want people with PMLD and their families to be involved in reporting on and evaluating the approach.

b) PAMIS would welcome local authorities setting out how they would provide RSHP education for people with PMLD. The use of the [PAMIS sensitive stories](#)³² and research might be helpful in supporting this.

c) PAMIS welcomes the setting out of service provision and the opportunity for people with PMLD and their families to be actively involved in their communities and to be able to participate in the evaluation of the impact of the services provided for them in their communities. However, we believe that there will be a need for explicit workforce education and support to enable this to be truly inclusive of people with PMLD, “how do you know what you don’t know” is a frequent question we pose to services with no experience of supporting people with PMLD and their families.

d) PAMIS would welcome the extension of this to Police Scotland and would support the commitment by Police Scotland to set out how people with PMLD and their families can report crimes and how they can have their voices heard. Again, this will require support and education of a cross sector workforce.

³² <https://pamis.org.uk/services/multi-sensory-storytelling/>

Proposal 5

PAMIS have experience of organisations not being accountable for even the very basic rights of individuals being met. For anything to progress there must be far greater accountability to ensure human rights around inclusion in communities and wider society are upheld. People with PMLD have some of the most complex health care needs and we recommend that they are specifically named in the Bill to ensure that they receive the correct health and social care as well as an understanding of the equipment necessary for them to enjoy a meaningful life and have access to the same life and everyone else. For people with PMLD to have access to the quality of life they deserve there should be specific mandatory training provided with ongoing support and supervision built in. This needs to be enshrined in law but whether a Commission or Commissioner can actively ensure this happens is debateable given the breadth of the proposed groups of people. Again, we want people with PMLD to be specifically mentioned and accounted for in any proposals going forward.

Q2. Which of these proposals do you not agree with? please tell us why?

There are no proposals that PAMIS disagrees with but the specifics for this group vary considerably within the framework of the questions. People with PMLD are a highly complex hidden group with very specific needs. The suggestions in the bill proposals and this consultation are important but our answers have highlighted the specific issues and requirements for people with PMLD in order for them to maintain and grow relationships with others and with their communities.

Q3. Is there anything else that we should consider which is relevant to this topic?

Relationships with other families, peers and communities.

Relationships are as important to people with PMLD and their families as they are for everyone else but due to the complexities of the health care needs of people with PMLD and the complex caring role of family carers it is often difficult to find opportunities that support the creation, development and sustainability of relationships. Lack of opportunities to foster relationships often leads to isolation and loneliness for both the person with PMLD and their families. Access to accessible, inclusive, purposeful and meaningful activities within their communities is a huge barrier for people with PMLD and their families. The development, provision and facilitation of accessible, purposeful and meaningful activities creates opportunities for relationship building with other families but also

creates an understanding of the needs of people with PMLD in their communities and means they become visible members of society. This relationship building is crucial for people with PMLD on so many levels.

Having friendships and relationships with their peers is crucial for people with PMLD but unfortunately out with school this is difficult to maintain, often leading to isolation and loneliness. The difficulties are often due to lack of provision of accessible venues that have a changing places toilet and the lack of purposeful and meaningful activities within their communities. This will often not just exclude a person with PMLD but has an impact on the whole family, siblings included. Children, young people and adults with PMLD are not always invited to birthday parties or social occasions because they are not understood and are overlooked by their peers, communities and even in some cases extended family.

The lack of lifelong learning opportunities for adults with PMLD is a barrier too and they often lose contact with peers on leaving school. Having access to lifelong learning opportunities and accessible, purposeful and meaningful activities creates an environment that is conducive to making friends and sustaining relationships both for the person with PMLD and for their families.

Consideration must be given to the provision of a changing places toilet to enable people to access their communities and purposeful and meaningful activities to help them maintain relationships.

Relationships with Health, Social Work, Allied Health Practitioners, Medical Profession and Care Support Staff.

Relationships with practitioners involved in the lives of people with PMLD and their families is often fraught with anxiety, lack of understanding and frustration at not feeling included as an equal partner in care and listened to by social care and health practitioners including allied health practitioners, nursing, the medical profession, and in primary and acute care settings. People with PMLD and their families often feel their voices are lost or their knowledge is not respected. This is backed up by research that highlights that health and social care teams do not recognise family carers as part of the team. The information and advice provided by the practitioners often feels fragmented, disjointed and fails to treat the person with PMLD in a holistic way. Families report to PAMIS that it often feels like each practitioner is working in isolation and not in partnership with each other. Relationships with care support staff too can often be fraught with anxiety, particularly around the ideas that it is seen as inappropriate to have a relationship with your staff. For people with PMLD and their families the relationship with staff that care for them 24/7 in some cases is crucial. This is obvious when

someone loses a long-term staff member, it is like a bereavement and for some of these families care support staff are the only people they see all day. For people with PMLD these staff are like a second family and currently that is frowned upon, this needs to be considered going forward. Staff also need to be supported to work within this context and there must be more consideration about the impact of loss on those being cared for especially in this context of relationships.

Section 7: Access to Technology

An earlier section of this consultation paper discusses, and makes proposals for, bringing a greater focus to how public authorities' duties around inclusive communication can best be met for neurodivergent people and people with learning disabilities. By enabling better inclusive communications, we would expect this to have a positive impact on increased digital access.

People with profound learning and multiple disabilities are among the most digitally excluded in Scotland. Relying on the support of others 24/7, they also rely on those others seeing the value of technology in their lives. Too often people who have profound learning disabilities lose access to technology that supports their voices and choices as a result of age-related transitions, or transitions into services that don't see the value of technology within their service. For many staff, learning an approach to technology becomes yet another task in a busy day that they are told to achieve. PAMIS support the view that staff need protected time, appropriate training and access to technology in order to support people with profound learning to benefit from technology.

Technology has huge potential for this group in supporting visibility, cultural inclusion, retaining skills, supporting conversations around consent, facilitating inclusion, addressing stigma and supporting self-advocacy. We are concerned that someone with profound learning disabilities needs to work disproportionately hard to gain and retain skills around technology and that those skills are highly likely to be lost very quickly if participation is not encouraged and practiced in a knowledgeable, compassionate and supportive way.

Unlike their peers and the wider Scottish population who use technology such as social media, e-mail, digital photography and videos to maintain family contact, friendships and explore and affirm their interests, people who have profound learning disabilities again rely on others seeing the value of this for them. They are once more in a situation of dependence on others seeing the value of their inclusion. There is a very real danger that the cultural identity of the individual with profound learning disabilities, who cannot communicate their own story will be lost if those around them lose the thread of their narrative. This devastating outcome leaves people with profound learning disabilities culturally isolated, losing friendships, relationships, family stories, narrative about their abilities, and examples of things they enjoyed doing. Access to the technology that the majority of us in Scotland use to share and explore our identities is vital for those who have a learning disability.

Proposal 1 - We could also consider how to ensure that training is available to people with learning disabilities in digital skills and online safety.

As a result of people with profound learning disabilities reliance on others 24/7 in all aspects of their lives including access to technology, Pamis would like to see this proposal extended to the families and carers of people who have profound learning disabilities. Training should be developed, adapted and offered in a way that is appropriate and that acknowledges the unpredictable nature of the caring role.

Proposal 2 - We could gather clear data on the number of people with learning disabilities and neurodivergent people accessing and using technology.

PAMIS agree that gathering clear data on the number of people with profound learning disabilities using technology would be useful and would emphasise people with profound learning disabilities be treated as a distinct group having distinct needs within the wider group of people who have a learning disability. PAMIS would further support data collection around access to technology across transitions, type of technology used, who is helping the individual with technology, and exploration and action around access to digital devices and technology equipment such as Eye Gaze. We also surmise that having this data will also support future planning.

Proposal 3 - We could make more support available to directly help people with learning disabilities and neurodivergent people access and use technology.

PAMIS support this proposal and assert that support should also be relevant to people with profound learning disabilities. Support to use technology must acknowledge the unique challenges and barriers to the use of technology and their reliance on carers to access technology in the first instance. This support should also consider the technology that is accessed within schools and children services following the child into adult services, with consideration for shared budgets.

Section 8: Employment

Do you agree with this approach?

PAMIS agrees with the proposed approach in the Bill to challenge new ways of working towards meeting the Fair Work First Principles and welcomes the inclusion of taking action to create a more diverse and inclusive workplace.

PAMIS also supports the inclusion of more specialised training being additional to standard disability awareness training and would welcome training being delivered by family as equal partners with highly specialised skills across many disciplines.

In terms of the employment of people with PMLD, PAMIS would encourage the idea of job coaches and educators. People with PMLD and their families are our best educators and would make excellent job coaches in educating others across many disciplines but particularly around supporting students in colleges and universities. We would like to see people with PMLD and their family carers fully participating in education and development across a range of disciplines from education, health, social care, and sport to name a few. The inclusion of people with PMLD in an education role within colleges and universities would ensure that we have a workforce that are taught how to communicate with and care for people with PMLD therefore avoiding expensive mistakes being made through lack of knowledge and understanding of PMLD. From early years practitioners, teacher training, to social care workers and all the other professions that will be involved in the lives of people with PMLD, if they were taught by PMLD coaches we would have a skilled and knowledgeable workforce who would learn how to communicate and care for people with PMLD. PAMIS would like to see opportunities for people with PMLD to be included and embedded in the principles of the Fair Work First³³ in the area of ongoing training and development and education of care staff in early years, across the sectors mentioned above.

Consideration also must be given to the employment of Family Carers of people with PMLD within this bill, both as advocates for their sons/daughters but also as individuals themselves. Their caring role is intensive, but this should not exclude them from seeking employment should they wish, and many have reported that employment is a lifeline for them. It is something that they value, and the opportunity allows them to be their own person. It improves their overall health and wellbeing both

³³ *Fair Work First Guidance – supporting the implementation of Fair Work First in workplaces across Scotland*, Scottish Government, March 2023.

physically and emotionally. However, there are many barriers that prevent them from accessing employment including lack of appropriately qualified care provision for their sons/daughters.

The implementation of “No One Left Behind”³⁴ states it aims to deliver a system that is more person centred, tailored and responsive to the needs of people of all ages who want to help and support people on their journey towards and into work and PAMIS would like to see people with PMLD and their family carers included in this programme both as educators and employees. Family Carers are experts by experience and have vast and valuable knowledge to contribute to education others. Family carers entering employment for the first time or returning to employment after a break in employment have a valuable role to play in educating employers and fellow workers about what is required to be in place to be a truly inclusive and understanding employer. In terms of Carer Positive³⁵ organisations, family carers have so much to teach employers about what that really means in terms of practice. PAMIS welcomes the opportunity this bill offers for people with PMLD and their family carers to be fully included in promoting and encouraging more inclusive practices and in furthering education, knowledge and understanding of PMLD within education and employment situations.

³⁴ *No One Left Behind*, Scottish Government, 2020.

³⁵ <https://www.carerpositive.org/>

Section 9: Social Security

What do you think?

The key difficulty people with PMLD face in relation to obtaining social security is the lack of understanding from staff about their lifelong condition and the complexities of this. In addition, there is very poor understanding on the practical demands facing family carers who will most likely have welfare guardianship powers and be applying for assistance on behalf of their loved one. Whilst PAMIS absolutely endorses Scottish Government's human rights-based approach to social security in Scotland we do believe that processes could be streamlined to avoid duplication of effort for family carers and reduce the intense stress they experience when applying for various benefits from multiple different places. There are currently different systems in place for the provision of social security and focusing on transitions to adulthood specifically, family carers currently must reapply for Adult Disability Payment at the same time as applying for all the other various elements which are available to assist with transition and potentially independent living. It is incredibly time consuming and impacts on the ability of carers of a person with PMLD to enter paid employment themselves with many reporting that applying for various components of social security being equivalent to a full-time job. The other main issue for family carers seeking social security support relates to the above mentioned lack of understanding of PMLD amongst social security staff in terms of allowing adequate meeting times and the availability of suitable spaces to meet and be supported by someone who fully understands their situation. PAMIS would be keen to explore opportunities around the PAMIS Digital Passport being used as a tool to help carers applying for Adult or Child Disability Payment. There is potential for social security online systems to allow the upload of the digital passport document (a simple, PowerPoint based file type) as part of their application and that social security staff are trained in the use of digital passports for people with PMLD and their carers. This would benefit all parties in understanding a person's needs and is a very visual method of painting a picture of what life is like for that individual. This could potentially help reduce wait times for assessment outcomes. The digital passport could also be used as a staff training tool. We would welcome the opportunity to explore various models of how this could benefit social security Scotland and their clients.

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: National and Local Strategies

PAMIS mentioned above the opportunity for using Digital Passports to improve processes for people with PMLD, their family carers/welfare guardians as well as social security staff themselves. This could potentially form part of an inclusive communication strategy strand with the main objective

being to better support people with PMLD to access the social security they are entitled to. PAMIS would welcome inclusive communication strategies that reported on and evaluated how they communicated with people with PMLD and their families throughout the assessment process. This evaluation should take into consideration the timescales families currently have to navigate while undergoing the assessment processes.

Proposal 2: mandatory training for social security staff

PAMIS would like to see mandatory training on how to improve communication and support for people with PMLD for all social security staff (as opposed to some.) We have been delivering training to front line staff at venues across Scotland for several years as part of an introductory module on Changing Places toilets. Our research shows that it is often front of house staff, cafe staff, reception desk staff, customer service staff, security teams and administrative appointment teams who families interact with initially that most benefit from training. Families have told us that having professionals who undertake assessment on their lives should have training on further communication because understanding someone's wants, wishes and views can only be adequately developed when the person assessing is able to communicate effectively with the individuals they are working with. We would strongly recommend taking advice from families themselves or PAMIS to determine which staff roles are identified for mandatory training. We would support the introduction of a statutory requirement for training on learning disabilities but would also want there to be a specific aspect on people with PMLD and an awareness of the impact of caring for someone with PMLD. The latter is important, so staff are aware of the intensity of the role and are supported to develop skills in sensitive engagement.

Proposal 3: Data Collection

PAMIS strongly agrees that more robust data collection is essential and that PMLD should be included as part of data collection for both CDP and ADP.

Q2. Which of these proposals do you not agree with? please tell us why?

n/a

Q3. Is there anything else that we should consider which is relevant to this topic?

In relation to determinations and redeterminations, PAMIS would argue that people with PMLD face the biggest barriers and are still affected by COVID 19 and their welfare guardians would benefit from leaving the COVID 19 exception in place to facilitate late applications. The principle of respect for the dignity of individuals is at the heart of the Scottish system and since many of the carers we support

cannot undertake employment due to the intensity and demands of their caring role allowing additional time and flexibility to request redetermination contributes to reducing poverty another principle at the heart of the Scottish social security system. In keeping with this there should be the ability for individuals to withdraw a request for redetermination. There should also be a legal duty for Scottish Ministers to continue to work on out of time redeterminations.

The key message from PAMIS – it is greatly important that flexibility remains available for applicants particularly for carers who are applying on behalf of a loved one using welfare guardianship powers or in the capacity of financial Power of Attorney. Many of the families PAMIS supports lead enormously stressful lives which very few professionals truly understand. The complex care needs of individuals with PMLD can frequently result in emergencies which must always take priority for family carers resulting in a need for greater understanding and flexibility when it comes to being able to achieve social security application deadlines. For most of the families we support, the caring role is intensive, 24/7 with very little respite and dominated by meeting the day to day needs of their loved one. It is essential that challenging personal circumstances are taken into consideration and the process to apply and evidence exceptional circumstances is as simple and straightforward as possible. The lives of the families we support are stressful enough and we welcome anything that can be done within LDAN Bill to make it is easier and simpler to apply for social security support.

Section 10: Justice

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: Strategies and a co-ordinated approach

We agree that there needs to be more interaction across the justice system. There is a lack of knowledge and awareness of neurodivergence and learning disabilities across the justice system as a whole and it is severely lacking in terms of understanding people with profound learning and multiple disabilities (PMLD). A single national strategy would support this process and would be helpful in avoiding undue and unnecessary stress for families. Any such strategy would have to consider the physical environment and the emotional impact that any contact with the justice system has on families. It would also have to include provision for accessible information relating to how the system works from the basic interviewing stage to the victim support offered by the system. This is currently lacking across the entire system.

Proposal 2: Data and the identification of neurodivergent people and people with learning disabilities in the justice system

Currently there is a lack of information around the whole understanding of the police and justice systems processes and the provision of this information is key for families. Information transfer is crucial both for people with learning disabilities and their families as a lack of understanding how the justice system works causes unnecessary stress for those involved. For example, letting people know what will be involved in the process of providing evidence such as, the fact that someone who is non-verbal cannot currently be interviewed therefore they do not have their voices heard within the system. Also, a lack of information and understanding by interviewing police officers leads to unnecessary and upsetting information. One example is that when a family carer was telling a police officer that their child has a profound and learning and multiple disability the police officer then asked the parent if they had a learning disability. Data and information sharing is crucial to avoid unnecessary trauma when a witness comes forward. Also, reasonable adjustments in the physical environment should be considered too as the standard interviewing environment is not currently suitable for many neurodivergent people or someone in a wheelchair. It is imperative that all this is considered in the identification of people with PMLD in justice system.

Proposal 3: inclusive communication

Inclusive communication is a key consideration when people come forward as witnesses as above, the process is often alien to victims and their families and the whole legal process of the justice system requires to be embedded into accessible information in language that families will relate to. From the interview process to the availability of victim support all requires accessible information exchange to appropriately support people through the process.

Proposal 4: Mandatory Training

Mandatory training is crucial and should be extended to other public bodies, however mandatory training alone will not provide the key to understanding neurodiversity and risks becoming a blanket approach for communicating with everyone. Mandatory training would be a first step to understanding marginalised groups like people with profound and multiple learning disabilities, but it is by no means the overall answer, it would require to be accompanied by monitoring of how this is being undertaken. It should also be provided to the Victim Support Service. Training should definitely be extended to police, prison, COPFS and relevant courts and tribunals staff as well as victim support.

Proposal 5: Advocacy

Independent Advocacy for people with profound and learning and multiple disabilities requires specialist health and social care knowledge and currently there is no advocacy service that has the knowledge or understanding of people with PMLD or the time it takes to understand how they communicate as evidence in the relationships section too.

Proposal 6: Diversion from Prosecution (DfP)

Diversion from prosecution should include better understanding of how those with more complex learning disabilities communicate through behaviours. Incidents occur because their needs are not being addressed and met and the only option left to them is to communicate through their behaviour. Understanding Communication and Behaviour should be a key component in any future training particularly for people with PMLD.

Q2. Which of these proposals do you not agree with? please tell us why?

The proposals are ambitious but there is nothing in them to disagree with. Again, the proposals are not all relevant to people with PMLD therefore these answers reflect what is required for this group.

The impact on families on involvement with the justice system is traumatic and what needs to be in the proposals is ongoing support for people with PMLD and their families' following interviews of incidents or involvement with the police where they have been victims. While PAMIS agrees with the proposals they do not include what is required for people with PMLD and their families.

Q3. Is there anything else that we should consider which is relevant to this topic?

PAMIS would like to see:

- better understanding of PMLD across the justice system for families.
- Better understanding and support for victims with PMLD and their families
- Understanding and access to appropriate and knowledgeable trauma support for victims and their families
- Better provision of information for families about how the justice system works, including the interview processes and procedures.
- Training that includes understanding communication through behaviours and an understanding of trauma informed practice
- Ways of being interviewed that are appropriate for the person and not for the system, such as offering online interviews with families and interviewing in building that are accessible to people with PMLD and where there is a changing places toilet to ensure personal care needs are met.
- Police statements that take into account the context of any recorded incidents and that demonstrate an understanding of communication through behaviour.
- Automatic referral to Diversion from Prosecution process is what would be required for people with PMLD.

Section 11: Restraint and Seclusion

Do you agree with this approach? Please tell us why?

PAMIS recognises, acknowledges, and supports the work currently being undertaken around restraint and seclusion however if the emphasis on this work does not place a mandatory duty on services that includes accountability, it continues to leave children, young people and adults with PMLD in a vulnerable position. This bill has a duty to address to this. Any changes in future legislation must consider full accountability. Guidance alone will not achieve the outcome required. It is imperative that the LDAN bill does more than simply highlight and reference the existing work being undertaken to enhance the lives of children, young people and adults with PMLD.

In relation to the comment within the bill which states that the “bill would not be the right place to do this, because it would apply to all children and young people”, we must make clear that children, young people and adults with more profound and complex needs often have communication difficulties including nonverbal communication, therefore they will communicate through behaviour and as a result are far more likely to be exposed to increased incidents of restraint and seclusion.

Communicating needs through behaviour increases the risk of incidents of restraint and seclusion and/or increased medication, which also comes with risks that often lead to diagnostic overshadowing of underlying health conditions. The complexities of supporting those who communicate through behaviour puts them at increased risk of being misunderstood and as a result, this bill must explicitly take this into account and while this may be covered by the legislation mentioned above, the bill has an additional duty to ensure that there is accountability, increased awareness, understanding, support and appropriate training for staff in education, social care and in acute hospital settings. Mandatory training is required but it must be meaningful and not tokenistic or a blanket approach.

PAMIS would like to see more robust accountability around the use of restraint and seclusion in every service that support people with profound and complex learning disabilities who communicate through behaviour. Therefore, this needs to be included in this bill in terms of accountability to ensure this group are not forgotten about. It is imperative that any work undertaken externally to this bill is not simply a reference in the bill but that it is actively woven in and viewed as part of this work going forward.

Section 12: Transport

What do you think?

Whilst we know there is an ambitious and wide ranging programme of work currently underway to make improvements for disabled people when travelling, despite all of this, the reality is that most people with PMLD are currently excluded from being able to use public transport due to fundamental barriers such as a lack of appropriate toilets and a lack of knowledge amongst transport staff about this group and the challenges they face in their daily lives.

Due to the current inaccessibility of public transport, many of the families we support rely heavily on private vehicles. PAMIS are part of the National Transport Accessibility Steering Group where our presence feels vital to advocate for and ensure the needs of people with PMLD are not lost amongst wider accessible transport issues and that the barriers facing this specific group are prioritised within the framework objectives and delivery plans and visible to Transport Scotland as well as other stakeholders and group members. This is a constant source of concern for PAMIS. It is vital that programme delivery plans and themes within the Accessible Travel Framework recognise people with PMLD and understand their specific requirements so that improvements can be made.

Without a significant improvement in the number of CPTs available at transport hubs in Scotland as well as on board different modes of transport then families and people with PMLD will continue to live isolated lives, excluded from their own communities and overlooked. Whilst there has been some limited investment in improving CPT access at key train stations there are significant ongoing practical maintenance and management issues arising. Waverley train station in Edinburgh is a key example being one of the most important CPTs in Scotland for people with PMLD, yet users continually contact PAMIS about the facility being out of order and unusable causing huge stress and upset for families. Ensuring design standards are met and the basics of successfully maintaining and managing a CPT within a transport hub are all issues that PAMIS can support operators with to ensure new CPTs are built fit for purpose. This must be given greater priority by transport operators.

We have been engaged in various project work across remote and rural areas of the country and have gathered evidence about the specific challenges facing families living in these communities and on the Scottish islands. Lifeline ferry services across the western isles are not accessible for people with PMLD whereas those between mainland and the Northern Isles have greatly improved recently with the introduction of CPTs on board the vessels crossing those routes. We have been working with families who have been completely isolated for many years on the Isle of Lewis due to the lack of appropriate toilets. For those people, a visit to the mainland is out of the question.

Community transport continues to present significant challenges for people with PMLD and their families. In recent project work PAMIS have been involved with one local authority area, a significant challenge to successfully delivering the project objectives has been difficulties in provision of suitable community transport for participants with PMLD. Some of the children involved in the project require a specific service called Dial A Journey, which is the only local service suitable for transporting people with PMLD who must travel in flat-lying positions. This service operates for individual journeys and is a great asset for families who require lay-flat or large equipment to access education, healthcare and leisure opportunities and other local services. This service is invaluable in supporting the delivery of purposeful and meaningful activities in the area, however there are still barriers which have been challenging for the project delivery team to overcome. This includes the cost of the journey when it is not used for education transport or hospital appointments, and recent reductions in the service have meant that people with PMLD who rely on it are unable to access events or appointments which may occur out with the limited availability of Dial-A-Journey. Any journeys which are undertaken on a Sunday, or in the evening, would now require ambulance transportation in this area, which restricts people with PMLD and their families from accessing their communities or experiencing life out with available bus times. For some families, who are unable to afford private transport, this already limited time schedule is further complicated by staff shortages, schedule changes or cancelled arrangements, making each journey a fraught one.

With most of the families we support relying heavily on their own private vehicle for transportation, the prioritisation of blue badge parking spaces is of vital importance and ensuring the number of spaces available is increased or maintained is a priority area. With the growing number of EV it is important that continuity in design guidance is created and that more accessible EV charging bays are available as currently many are not fully accessible either by lack of appropriately sized bays and hatching or through the lack of drop kerbs.

In relation to transport to health and social care, PAMIS support the Mobility and Access Committee for Scotland's requirements that transport should be integral to care plans and user requirements to be better joined with NHS Boards, Local Authorities and the Scottish Ambulance Service.

“The following is also a huge problem for independent wheelchair user inpatients who travel to hospital by emergency ambulance or by helicopter: emergency ambulances and helicopters cannot take wheelchairs with the patient, particularly powered wheelchairs which don't fold and often weigh hundreds of Kilos. Emergency ambulances do have the floor tracks in which to tie down wheelchairs, but they don't have the necessary wheelchair tie-down straps (and when they have been offered the wheelchair owner's ones in the past, they have refused them as they haven't been risk assessed).

They would also have to remove the trolley stretcher (and leave it somewhere) in order to tie down such a wheelchair. When asked why they had the tie down tracks in the floors of all ambulances, I was told that they could tie down a baby incubator but that is only because the tie-down straps are attached to the legs of the incubator. So we frequently have independent wheelchair user patients taken to hospital by ambulance who may be taken 100+ miles to the Hospital in Inverness or 240+ miles to hospital in Glasgow and have to stay in hospital (often for weeks) without the wheelchair they have been assessed as needing (and had provided by the NHS). No attempt is made to reunite them with their wheelchair (and they get no visitors because of the distances involved) and they become dependent on others, forced to be pushed in hospital wheelchairs or on trolleys (often totally unsuited to their needs) and lose muscle tone which sometimes they may never recover.”

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: National and Local Strategies

PAMIS agrees with RTP’s being required to set out in their transport strategies how the specific needs of people with learning disabilities including people with PMLD are being considered and met through travel information systems and accessibility initiatives. We also support a requirement to set out in RTP travel strategies how staff across different modes of transport are being trained in disability awareness but the priority for PAMIS would be ensuring there is a PMLD specific component to this particularly as this group are most often non verbal and use other means of communication.

Reporting on the uptake of this is welcomed but as detailed in our wider response to the overarching theme on strategies as well as mandatory training this needs to avoid becoming a tick box exercise.

Proposal 2: Mandatory training

We strongly support mandatory training for transport workforce.

Passenger Assistance and Accessibility

For people with PMLD and their carers who are making use of taxi services or public transport to access their support services, like day service or respite, passenger assistance and support are integral to their ability to attend these services. Currently in one area of Scotland where we are delivering support, a number of transport services are being reduced, which is impacting on individuals who must attend a service 15+ miles from home and who must be transported there daily. In instances where the solution is the use of taxis or public transport, care support is currently being denied. This leaves vulnerable adults who are nonverbal unable to request support or alert their driver if an emergency arises or a medical emergency occurs. With appropriate training for transportation

staff, individuals requiring support during transportation should be able to access this support readily and consistently.

Section 13: Education

Q1. Which of these proposals do you agree with? please tell us why?

Proposal 1: Strategies and reporting requirements.

This proposal is a positive step toward integrating the articulation of the needs of all pupils with the statutory reporting duties already in place. We agree that this is a productive step to tailor reporting to the progress of supporting children and young people with additional needs but would like further consideration to pupils with PMLD who have complex needs and barriers around accessing education. We also believe that a national standard requires to be set which is clear on what is expected and not interpreted 32 different ways.

We also believe that creating an education system where children with PMLD can thrive must consider the barriers these children may have, unique to their complex needs, to education which often fall out with the standard academic recognition of reporting duties. Reporting on the educational needs of students without considering the practical and physical support requirements around those needs would create a false picture of the education access for students with PMLD.

This proposal would be successful in our view if it was inclusive of the following things:

- Physical access to education buildings, e.g.: reliable, tailored, safe and accessible transportation to and from the school, widened doorways to accommodate for larger wheelchairs and equipment, (a minimum of 1000cm), changing places toilets, and appropriate additional staffing and support. Without these provisions, a child's access to education is limited before it begins.
- The impact of the caring role on the parents and family carers of a child or young person to access education.
- A specific and targeted approach to identifying and reporting on education goals which align to a child's specific needs. Ensuring that more paths are available for children with complex needs, which focus on their human right to choice, independence and inclusion is key. This should be considered in reporting through the acknowledgement of the limited pathways currently available, and targeted efforts to overcome these limits.
- Reporting for academic purposes which uses GIRFEC or the SHANNARI Wellbeing Wheel should be sensitive to how these markers are measured for a child with PMLD, as well as the language they use to report on it. Families face stigma around disability and achievement, and reporting which likens their academic trajectory to other groups of children with disabilities may diminish their profound and incredible ability to achieve.

- Consideration of early years learning and access to inclusive nurseries.
- Understanding of the need for lifelong learning especially for young people and adults with PMLD. Their learning takes longer to embed and grow, if not sustained skills are rapidly lost. This must be considered in terms of education and pathways going forward.
- Consideration of how the complex healthcare needs are to be supported within the school environment and contingencies for staff absence that does not entail the child or young person with complex needs being the first child to be asked not to come into school. We are aware that currently this is a regular occurrence and the child with PMLD is the one whose education is impacted upon.

Finally, we would suggest that teachers are enabled to educate and not be expected to be the person to carry out health interventions. Teachers need to be valued in their role, enabled to develop effective educational interventions, and supported by health and social care practitioners. A whole team approach is required for children and young people with PMLD if they are to be enabled to thrive within education settings.

Proposal 2: Mandatory training for teachers, practitioners and other educators

We agree with this proposal and would like to expand on by highlighting the critical need for understanding the unique needs of children with PMLD. Before being put into post where a teacher is to deliver curriculum to children with PMLD, teachers should be required to undertake practical and supervised mandatory training which will give them a context for understanding what PMLD is, and how it may help to shape their classroom culture. We would propose the involvement of family carers and their child with PMLD in the design, delivery, and evaluation of the training. They are experts in the care and aspirations of this group and will support the collaborative approaches required to get the best for this group of people. We would also encourage across sector and across professions training and action learning – again harnessing the need for collaborative wisdom and working to ensure this group of children and young people are successfully engaged in education.

Professional learning opportunities and CPD for teachers who work with children who have complex disabilities would be beneficial around the following topics:

- Postural care and management. Ensuring appropriate body positioning during time in education settings will ensure safe, sustainable and supported physical stability for a child so that they can engage in their education positively. Postural management is recognised in broader Scottish policy¹ as contributing to safer airways, increased wellbeing and better sleep. In addition, moving and handling awareness and for classroom assistants and care

staff courses specifically related to the movement of children and young people with PMLD.

- Understanding communication and behaviour - children and young people with PMLD need their educators and support teams to have an understanding and awareness of the ways they may communicate which go beyond the spoken word. This training should be bespoke where possible, including the children or families with which they work.
- The impact of health inequalities, stigma, and access barriers to educational achievement. An understanding of this is critical to improve the outcomes and opportunities for children and young people with PMLD so they can achieve included lives that consider their wishes, wants and needs as a part of their educational experience.

There will be a team of allied health professionals who can support the areas mentioned however we would also suggest as previously having parent involvement could also enhance the delivery.

Proposal 3: Data

We agree with this proposal, as understanding the demographics of pupils who need support is a positive step toward achieving appropriate planning in curriculum, staffing and inclusion. The data does need to also identify those with complex needs to adequately plan future provisions and adaptations to environments as and when being developed. More robust data that accurately reflects the support needs and experiences of children and young people will support more appropriate academic experiences for children in education. Specifically for children with PMLD, the use of data could contribute to recognising their achievement markers, positively supporting their lifelong trajectory, and developing the tools and opportunities that children with PMLD need to grow into included adults who can thrive in their lives.

Q2. Which of these proposals do you not agree with? please tell us why?

PAMIS supports these proposals but, as with each section, feel they do not meet the needs of people with PMLD who access education as a child, young person or young adult. Children with complex needs require complex solutions that are sensitive, specific and multi-faceted in their approach. We feel that consideration to understanding the current needs and future goals of children with PMLD is a critical part of ensuring they can achieve in education, and this is inclusive of their physical access, aspirations and recognition of barriers.

Q3. Is there anything else that we should consider which is relevant to this topic?

Whilst we have included our considerations under each relevant proposal, there are some overarching themes which PAMIS believes must be considered:

- More comprehensive understanding of the meaning of PMLD
- Better understanding of the complex caring role of family carers, and how it impacts a child's education.
- The physical space and access barriers in education settings which can make positive attainment a difficult outcome to meet for children with PMLD.
- A change in the narrative and expectation that children with PMLD will grow up, instead of an expectation that they will not survive.
- Early years intervention for children with PMLD and the provision of accessible, inclusive nurseries with well trained and supported staff.
- Clearer pathways toward the continuity of education and learning at transition, so children with PMLD are not left without options when they leave school.
- A proactive approach to physical, cognitive and sensory support so that children can engage academically at the level which is identified to be appropriate for their needs.
- Multiagency and multiprofessional education with support to put learning into practice and ongoing support and supervision.
- Opportunities for children and young people to influence and educate others. Their expertise in team working, caring, compassion and inclusion could grow compassionate communities for future generations.

Finally, we want to ensure that education is continued throughout life. People with PMLD have the right to a life of meaning and purposeful activity. The United Nations highlights that inclusive education for all learners at all levels is a fundamental human right of all persons, including those with disabilities. However currently 'all' does not include people with PMLD in relation to lifelong

education. For many there are no opportunities to carry on their learning journey once they leave school. Their learning journey takes longer, requires consistency and ongoing development. PAMIS family carers have for a number of years spoken about the development of a lifelong learning model where their relative could continue to develop skills and integrate achievement into their lives. PAMIS are developing educational resources that support this concept and engage paid and family carers in supporting a multisensory journey of education and development. They are building community partnerships enabling the development of this approach into a broader range of community-based opportunities.

Section 14: Children and Young People, Transitions to Adulthood

Q1. Do you agree with this proposal? Please tell us why?

PAMIS agrees that there are aspects across the overarching themes as well as those in specific thematic sections of the Bill that could support more effective transitions. We highlight key areas below.

However, we are concerned that there is very little detail or consideration given to **health transitions**. This is a critical transition for people with a profound learning and multiple disabilities (PMLD). The lack of a clear transition pathway into adult health services, with no one practitioner to support it means that many young people do not access appropriate health practitioners and interventions. We also recognize that the expectation that many children and young people with PMLD will not reach adulthood means that services are not prepared for the young people. There is no coordinated approach and family carers find themselves taking on a full-time role, many having to give up work, to navigate the adult healthcare service with multiple appointments across various specialisms that their relative may require to see. As a child, they will have access to a dedicated pediatrician and associated team who will oversee the total healthcare. As an adult they may be attending 4,5,6 specialist consultants and teams and with staff who may have limited experience of working with people with PMLD.

Due to the lifelong and complex nature of a person with PMLD, the abrupt end of service and support is a deeply traumatic experience for many families - a loss of services, with nothing to replace them. At present, many people with PMLD lose access to vital therapies and services which allow them to access the world and their human rights with the best possible quality of life. When school finishes, it has been reported by our families that access to services like physio, hydrotherapy, occupational therapy, speech and language, respiratory, and feeding support are no longer accessible. These individuals become subject to long waits, re-assessment and loss of services which they have previously received and for which their needs have not changed.

PAMIS would like to see, as we also highlighted in the health and wellbeing section of the Bill, the recommendations from the Brown et al research regarding health transitions for young people with complex care needs taken forward and a legislative demand that a learning disability nurse coordinates the health transition of a person with PMLD into adult services.

We support the use of the PAMIS digital passport not only as a tool for the person with PMLD to support others to communicate with them and understand their preferences and needs, but also as a

training tool to support the workforce to deliver effective and appropriate care. The passport can also be a means of supporting inclusive communication and gathering the views and aspirations of the young person with PMLD.

We also recommend that a PMLD hub is established in each HSCP (Health & Social Care Partnership) as a Centre of PMLD excellence where the specialisms relating to PMLD such as nursing, neurology, gastroenterology, dental, orthopaedics, allied health professionals, GP (General Practices) services and many others could coalesce under the leadership of a named professional. This would replicate what happens in children's services and would ensure a person-centred, anticipatory, holistic care. It would also provide an opportunity to coordinate appointments and interventions taking part of the stress of managing multiple appointments away from the families. This should be led nationally to ensure that best practice is delivered locally. Local policies should ensure that the PMLD hub feeds expertise into all areas of policy and practice. This will enable the visibility of people with PMLD within service planning and provision whilst also creating an effective educational model for staff within local areas who currently have no experience or expertise in developing and delivering services for this complex group.

Essential to effective transitions is the understanding of the complexity of need and **data** on numbers of young people with complex care needs coming towards transition. This data and expectation of people with PMLD living into adult hood requires to be fed into local planning and strategy. It impacts on all areas of health and social care, all of whom require to communicate and coordinate their inputs and services. Planning for the transition of this group of young people requires to start early and data sharing on numbers and complexity of care should allow for adequate housing, workforce planning and service provision for lifelong learning opportunities, as well as specialist healthcare.

PAMIS has grave concerns about the current lack of appropriate adult provision of services for people with PMLD across the spectrum of health and social care services. Again, this relates to the lack of expectation that this group of people will make it to adult life. There is inadequate respite, no appropriate housing, in some instances no day services and certainly no opportunity to engage in lifelong learning.

PAMIS would like to see local and national strategies that ensure that appropriate planning and provision is provided for people with PMLD as they enter adulthood and beyond. This will also include appropriate **health and social care workforce education and development**, so they have the appropriate skills, knowledge and values to support this very complex group and their families.

Transition to adult services frequently sees the loss of known and trusted respite and short breaks. For many families the support from CHAS has been invaluable and there is a real sense of loss when the young person moves into adult services and loses this very specialist and indeed very special service. This transition is often missed within local planning. There were helpful insights into supporting positive transitions within the Scottish research *Future Transitions in Palliative Care*.³⁶

Workforce development also featured both at under and postgraduate levels and should be noted within the **Workforce** section within the Bill.

Local **strategies** must advocate for increased partnership working across all agencies, and a real emphasis on local authority children and families and adult social work departments. As previously mentioned, data about the needs of this group needs to be collected many years before transition so appropriate planning can take place. There needs to be a mandate for effective communication, sharing of information and forward planning between children and adult departments. Timely allocation of adult social worker will reduce the prolonged period of stress, strain and anxiety parents experience during the transition from education to adult services.

We support the current best practice guidelines and the many decades of research about how to make a transition good. What is lacking is the ability to transfer best evidence into practice and we recommend that there needs to be an enforcement of this. We know that parents benefit from clear communication regarding the transition process and an acknowledgement about their vital role within this process. We know that this needs to be highlighted at an early stage with practical information and support about future options – e.g. contact names and numbers, addresses etc.

We know that assessments must be completed jointly and co-produced with parents/carers, education and services to provide a clear understanding of the level of support the young person requires, the frequency and if this support can fluctuate (overnight support, increased support due to ill health, menstruation etc). Early agreement of budgets is essential to enable transition plans to be implemented prior to the young person leaving school and time for staff recruitment and training. But this does not happen, and any proposals made within this Bill need to consider how putting what we already know into practice can be enforced.

A recognised period of “induction” is essential for individuals with PMLD to new staff and services. We also want to see national and local support to ensure that all new staff can “shadow” within the school environment before the young person transitions into the adult world. This provides time to

³⁶ French , T., Raman , S., & Jindal-Snape, D. (2019). Future transitions in palliative care: care across the life course for people with life-limiting conditions. Scottish Universities Insight Institute.
pg. 92

build a relationship, understand the individuals' physical disabilities and the various aspects of daily support they require to ensure these needs are met and the young person remains healthy and well.

How to support the young person to participate and engage in activities, their communication methods, and their preferred means of interaction as well as any distressing behaviours they may experience is also essential as is an understanding of underlying health care issues and the necessary support individuals require as well as any postural care needs. All of this can be stored and shared via the PAMIS digital passport. Adapted from the traditional communication passports, they are personalised e-books of videos, sound recordings, photographs, and text about the person with profound disabilities. It enables aspirations to be captured as well as an opportunity to support those delivering care in how to enable these to happen.

We recommend that every young person with PMLD is supported to develop their personal passports as they transition into the adult world. Indeed, we would recommend that these are developed at a far earlier stage so that all tacet knowledge obtained by those involved in their lives over many years, can be pocketed and shared with continuity.

PAMIS and the families we support also have rising levels of concern over the limited day opportunities for young people at transition ages. Pre COVID people with PMLD were already experiencing issues in accessing appropriate purposeful and meaningful day opportunities. Their need for structure, support for their physical health needs and access to appropriate venues that had resources and equipment to meet their physical needs was frequently not being met. When the pandemic hit all access to day opportunities was lost and for many this has not returned to prior levels and for some, there is now no service at all. The impact of the pandemic and the loss of services and input has seen a regression in skills obtained whilst for many, skills have been lost resulting in a significant deterioration in wellbeing. This, combined with a social and health care workforce crisis, is further diminishing the opportunities for people with PMLD to access appropriate lifelong learning activities. There are gaps in the skills and knowledge of a transient social care workforce which will continue to limit the aspirations of the most marginalized within our communities.

Evidence from people with PMLD and their family carers, gathered through the PAMIS digital passport, highlights the need and aspiration to continue a lifelong learning journey. A positive future must be built for young people and families should not be expected to simply take what is on offer as so often this is not appropriate for people with PMLD. Lifelong learning is critical to retaining skills that these young people have spent their lives developing. Whilst college courses for life skills are

available, these often focus solely on aspects of living which are not traditionally available to people with PMLD. College courses must be available under a wide provision of skills and accessibility, in locations which can accommodate the support needs of people with PMLD. This is an urgent need for families, as more young people transition out of school and into unsuitable services, leading to higher numbers of out of area placements, young people in settings designed for older people, and young adults who begin the next chapter of their lives with a traumatic severing of every routine and relationship they have built during childhood.

Due to the complexity of needs individuals with PMLD present with, and the increase in life expectancy, consideration and planning needs to focus on **housing and supported accommodation** as more parents and carers recognise the impact the ongoing care and support role has had on their physical, emotional, psychological health and wellbeing. We have highlighted in the housing section our views for people with PMLD.

Question 2: which of these principles do you not agree with?

We do not agree with collecting further data on what people with PMLD and their families want from a good transition. For decades it has been recognised that the transition from education to adult services and beyond has been extremely problematic and has a detrimental impact on the health and wellbeing of those who are transitioning and the parents and carers who are supporting young people to transition. There has been a huge amount of research and data collated over many decades to reflect the many issues associated with transition as already mentioned within this consultation as well as what best practice looks like. Families supporting individuals with PMLD have told us that they need successful, well planned, co-produced and adequately funded transitions to happen as standard rather than the “post code lottery” that is currently in operation. Action is required immediately and with urgency to improve transitions. Utilising the data and evidence that already exists will enable the process to improve rapidly.

Question 3: Is there anything else that we should consider which is relevant to this topic?

PAMIS currently provide direct family support to families across Scotland who have relatives that are beginning the transition process from children’s services and education into adult services. Within Glasgow City there is a specific transition project providing intensive support to families. All local authorities implement various procedures and processes to aid and support transition, some shining the spotlight on good practice and successful transitions. At the time of writing, for the families that PAMIS support, the harsh reality is the school term ends in 12 weeks, for some families as little as 8 weeks, yet none of the families we are currently supporting have a budget agreed, a positive

destination identified or a transition plan in place. Worryingly, many of these families have yet to have an adult social worker allocated to enable the transition process to move forward. Immediate action is required and an ability to assure that services are developed and delivered to a group who are being seriously failed.

We have put forward proposals elsewhere within this response for an alternative model for supporting people with PMLD in the form of PMLD Hubs. This could also be explored as a new model to tackle the entrenched barriers we highlight above relating to the transition of young people with PMLD. This group are small in numbers but require an intense level of support from a highly skilled group of practitioners. Therefore, should we have a birth to death service for children, young people and adults with PMLD? A PMLD hub that straddled children and adult services could provide effective health and social care and pre-empt the many areas of concern that families share with us. In the long term, this would reduce costs, ensure appropriate high-quality services and most importantly, reduce the emotional distress of both the person with PMLD and their families.

Part 4 – Accountability

Option 1: A new Commission or Commissioner

Option 2: Better resourcing and additional duties for an existing body

Option 3: Champions and Advocates within Public Bodies

Option 4: Better resourcing for existing Disabled People’s Organisations who support neurodivergent people and people with a learning disability.

Option 5: Supporting good practice through standards, guidance and practical tools and investing in co-production.

Which of the 5 options set out above do you think would best protect, respect and champion the rights of people with learning disabilities and neurodivergent people? You can select multiple options if you wish.

PAMIS are unclear about whether any of the current proposals will actually deliver effective change and ensure that all people with a learning disability, autistic people and neurodivergent people will realise their human rights. Currently we are so far away from this vision it is difficult to ascertain what needs to happen to get there.

PAMIS are concerned that all the proposals do not have the teeth to enforce change. We have a number of commissions and commissioners already, as highlighted in the research and consultation but what have they actually achieved for people with profound learning and multiple disabilities? Their lack of ability to enforce action even when human rights have been blatantly breached means we must consider how to regulate in a way that compels actions.

As we highlighted at the beginning of the consultation in terms of reach and definition people with PMLD are one of the most marginalised groups of individuals within our community, and a part of a larger group of people who also have their human rights limited. They live with challenges of a cognitive ability of around 2 years, and most have health issues such as epilepsy, respiratory difficulties, digestive issues that may require them to be fed via a gastrostomy, and body shape issues that can impact on all the above health issues. Most also live with sensory problems and have little or no verbal communication. They need people to develop understanding of how they communicate and to empower them to have their voices heard. Despite all their challenges, PAMIS describe profound as meaning deep, intense, wise, requiring great insight or knowledge and although many people with PMLD have significant areas of disability they also have unique areas that never cease to surprise those who care and work with them. They make a unique contribution to the lives of others, not least

in what they are able to teach about how to care, how to act with compassion and how to make human connections.

The complex caring role for those supporting a person with PMLD is exhausting, emotional, intensive. The caring role is made even more difficult because of the invisibility of this group which means that many in positions of power in terms of service and funding provision, may not have met someone with PMLD and have no understanding of their complex needs, of their aspirations, of the quality of their lives when the right support is provided. Those in power may also not have insights into the complex 24/7 caring roles. This invisibility has for many years been reported by families as the reason that they “have to fight for everything” they need to support their child or adult with PMLD.

During COVID families were stripped of their rights, no recourse and even with Scottish government direction public bodies ignored and continued to not only breach human rights but continue to deliver approaches that impacted adversely on the lives of people with PMLD, at worse contributed to their early mortality. This disregard continues. It is inconceivable to think that public bodies on any level would feel this is acceptable and, in any ways, justifiable.

One family have been fighting with their local HSCP for the last 5 years to get an acute hospital pathway for their daughter with PMLD, ensuring that her known paid carers were able to accompany her into the hospital. Without familiar staff the person with PMLD is at risk, as might be others when fear takes over and distressed communication is displayed. At one point this person was sent home without treatment because social work refused to allow her care team to accompany her into the acute hospital environment. This injustice, unsafe practice, lack of care and common-sense approach has forced the family to engage with a number of the current Commissioners and a Scottish Government Minister who provided a written mandate but has still not had an appropriate result. Everyone that has had heard about this acknowledges the approach the family are demanding as key to protect their daughter’s safety, but no one appears to have the power to enforce this. This example highlights our concern that none of the current proposals will have any impact in changing the outcomes for people with PMLD or the wider community of people with a learning disability.

We are also concerned that even with legislative powers some public bodies will still breach what is asked and we want to know what the recourse would be? PAMIS were told that they had a case for a human rights breach during COVID but that it would not be successful because even though the local authority were guilty, they had the funds to draw the case out and make us bankrupt.

The role of a regulator, a body to enforce action with penalties that actually make a difference is required. We are not convinced that we have the right proposal currently to take this forward. Perhaps there are more lessons to be learnt from other bodies in other industries?

PAMIS believe that fundamentally there must be a shift in the balance of power and that local authorities and HSCPs must be held to account, and this must be enforceable.

Option 1: A new Commission or Commissioner

As highlighted above PAMIS are not convinced that there is an option that currently will deliver what is required. If we are to go down the route of a commission or commissioner, it would require powers that are currently not available. We also highlight that a 'recommendation' is just that and will not deliver change. The size of the neurodivergent community, people with a learning disability and autistic people is too big for one commissioner to support and even with a commission how will the priorities be set for taking forward an already full agenda of issues and breaches of human rights? People with a profound learning and multiple disabilities are invisible, not included within their communities and we would worry that their voice will not be heard, a drop of water in an ocean. And yet if we get it right for the most discriminated and marginalised, we frequently feel the ripple across communities.

Option 2: Better resourcing and additional duties for an existing body

As we highlight above the invisibility of this group is a concern and we would require to see how an investment would support the visibility of groups such as people with PMLD within each of the current commissions. Currently these are failures in upholding the rights of individuals with PMLD and their families within these bodies and we would question how impactful they are able to be with their current powers and size. A large investment in expertise would be required and assurance that marginalised and invisible groups such as children, young people and adults with PMLD and their family carers would be visible within work plans. The investment in a specialist team with the knowledge and skills to represent a number of subgroups within the Bill would be required. We also echo the issue about requiring power to act – recommendations do not make changes, teeth/enforcement with consequences for failure are required.

Option 3: The Scottish Government have Champions in Scottish public bodies.

The model of champions over many years has not been successful. PAMIS are also concerned that this then becomes a siloed approach unless there are clear goals about the role of these Champions. There are many strategies that impact on people with PMLD because of their complex healthcare and profound cognitive and sensory issues. We need public bodies to become more aware of who is in their communities and to engage directly with them otherwise we will revert to the sinister issues that came to light during the pandemic. If Champions were facilitators with an ultimate goal of developing the knowledge and capacity within public bodies but not in being the voice of those who the Bill supports, we could see some benefits to developing this role. But lessons need to be learnt of where these roles have failed to increase public body awareness and responsibility in the past.

Option 4: Scottish Government could give extra resources to existing Disabled Peoples

Organisations

We believe that DPOs have a role to play in accountability and that for all of the suggested options they would add the voice of the people being impacted.

PAMIS are not classified as a DPO although half of our governing Board are family carers of a person with PMLD and they ensure our focus is always on the best outcomes for this group of people. We are the only organisation that solely supports people with PMLD and their families to lead healthy, valued and inclusive lives.

Our resource is reliant on public body contracts such as local authorities which means that our intense family support service is not across the whole of Scotland. It also means that when we support families in raising issues with local authorities, we are at risk of having funding cut as happened in one area. We believe in partnership and collaboration but will not be silenced by funders. We provide national projects across Scotland but are not able to provide the intense family support to these out of area families that is required particularly at this moment in time. However, we have been modelling different family support in these areas, supporting families to access their local communities and to build up the visibility of them and their relative with PMLD. In addition, we are suggesting that to deliver a human right, evidence based and lead in research that is required to overcome the decades of no curiosity into the causes of ill health in people with PMLD, a PMLD hub should be developed in each Health Board in conjunction with their HSCP. This would bring the expertise of specialist practitioners in the area of people with PMLD across the public and third sector alongside researchers and family carers. This will provide a united voice in terms of realising rights and driving change and can be the centre for consultation. It would facilitate meaningful engagement

and consultation to ensure that the narrative changes to one of expectation of full, meaningful and inclusive lives. PAMIS as part of the PMLD hubs could support and influence accountability, as part of a process, it can amplify the voices of people with PMLD however the issues about secure funding, and being independent of local authorities would need to be addressed.

Option 5: Scottish Government could make new Standards.

PAMIS believe that instead of writing new standards the existing standards that are based on evidence and best practice should be enforced. We think that public bodies should be held to account when breaching these standards, there should be penalties for non-compliance and that reviews when conducted have enforceable actions.

New standards and indeed the current ones must be considered through the lens of a person with PMLD. This must be done in partnership with the family carers and organisations with appropriate expertise and skills in working with people with PMLD and their families. We highlighted in the complex care section the previous model of peer review of standards for people with a learning disability and how much more effective that process would have been if the Health Boards has been compelled to deliver on the actions, recommendations do not force actions.

We also want implementation guides to be provided that ensures there are no opportunities to provide individual interpretations, no ambiguity and support to ensure that implementation supports people with PMLD.

In conclusion PAMIS have no clear preference to the options described, currently we do not believe any of them will deliver what is required. There is a need to further consider authority and enforcement. We also believe that aspects of option 3, 4 and 5 would further support the rights of people with PMLD and support option 1 or 2.

Please give reasons for your choice(s).

Combined in the text above

Are there any other options we should consider? Please give details.

Combined in the text above

APPENDIX

Transition Case study Fife.

Background

A...Is a young woman who left school in December 2023, the family have been on the PAMIS database for 8 years and have mainly accessed PAMIS services through leisure activities. A's.... Mum contacted our Family Support Service in September 2023 to inform PAMIS her daughter was due to leave school and had not been appointed an adult social worker. Without an adult social worker, no adult assessment or budget could be approved. Mum asked the family support director to attend the next scheduled meeting and support her with the transition process, she described herself and been extremely anxious and concerned for the future. A...is a happy and well-loved individual who have very complex health care needs. A...loves attending school and routines are particularly important to her, when A becomes distressed, she can present behaviours and can stop eating if she is too anxious, putting her health at risk.

Appointment of an adult social worker

An adult social worker was appointed at the end of October, meaning the transition process would only be 5 weeks, instead of 5 to 6 months which is normally allocated. The October holidays were particularly distressing for Mum as her daughter presented behaviours which were challenging. In transition meetings a placement was identified and presented to funding panel in November 2023. Mum was satisfied with the support offered and it was hoped a placement could start in January 2024.

January 2024

A...left school at the end of the school term and unfortunately due to staff shortages is yet to access the service. Mum is now fulltime carer for her daughter without any support. Mum also cannot work and has little or no time to access any form of respite, Mums emotional and physical wellbeing is in jeopardy. The family support director has continued to work with mum and social services. There have been further meetings with a service who will be able to provide short support for mum in the home before a place adult day services can start.

Support and work completed by PAMIS.

1. Offered emotional support to Mum, many calls were received and made to mum as she felt very overwhelmed and anxious about the future.
2. Attended each transition meeting from September to support mum and raise concerns about the timing of the transition.
3. Contacted Social services to request a social worker is appointed as a matter of urgency.
4. Letters of concern were written to local MSP and councillor. Both the MSP and Councillor engaged following the letters of concern and offered to support the family.
5. During conversations with Mum and Adult Social worker the family support director offered knowledge on current services being offered in Fife.
6. Completed a carers support plan on behalf of Mum.
7. Arranged visits and visited services with Mum. There was also follow up dialogue with Mum to discuss her thoughts on the services.
8. Continued to support Mum after her daughter left school through emotional support and engaging with social worker on behalf of mum when necessary.
9. Support Mum with ILF funding for suitable activities for her daughter to attend.