PAMIS response to Rule 8 request relating to impacts

This Rule 8 Response only relates to impacts. A full response will be submitted in due course.

a. A brief overview of the history, legal status and aims of the organisation or body, where relevant

1. The Profound and Multiple Impairment Service, better known as PAMIS (Promoting a More Inclusive Society) is registered as a charity in Scotland (SC038601) and in England Charity Registration Number of 1011895. PAMIS, (website: www.pamis.org.uk: https://www.facebook.com/pamisscotland), founded in 1992, is the only charity that solely supports children, young people (CYP) and adults with profound learning and multiple disabilities (PMLD) and their families to lead healthy, valued and included lives. PAMIS offers a range of projects and programmes including: family support services; education and development; research and practice development; inclusive culture and leisure; campaigns; information sharing and our library including the PAMIS multisensory stories; advice and registration of Scottish changing places toilets and resources to support digital inclusion.

2. This core work supports PAMIS's founding objectives that:

- people with PMLD are valued both as individuals and contribution they make to the community.
- people with PMLD should receive all the support needed to realise their full potential.
- people with PMLD have a right to a full life shaped by personal choice, abilities and needs and that this underlies all provision and policy affecting their lives.
- the knowledge and experience of family carers is recognised, and that their views are fully taken into account in service development.

3. PAMIS has spent 32 years listening to and working with this group of people and their family carers. It has built research and practice that supports this group to be included and valued within society, albeit slowly and with much still to be done.

4. 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.

5. PAMIS has continued to deliver on the four principal aims on which it was established. These were to:
    a. Give practical and emotional support, advice, and training to the families of one of the most marginalised groups in society, i.e., people with profound and multiple learning disabilities (PMLD)
    b. Offer advice and information to professionals in social, education and health services and other voluntary sector agencies regarding support for people with PMLD and their families.
    c. Contribute to and influence policy and practice in order to ensure families and their PMLD relatives have an optimum quality of life.
    d. To undertake research studies on specific aspects of health,
    e. education, social care that impact on the lives of people with PMLD and to apply the outcomes of such studies in training and information sessions for family carers and relevant professionals.
6. The PAMIS 10-year strategy builds on this, recognising that change takes consistency in messaging and action over time, and ensuring support, service, innovation, education, and development to support the most marginalised within our communities.
7. PAMIS delivers education and development opportunities to those supporting people with PMLD across sectors and communities, including health and social care workforce present and future, business tourism, architecture, and place designers.
8. PAMIS has built a model for education that supports family carers and people with PMLD as educators, delivering a range of training and development opportunities and co-training on courses such as the postural care training , bereavement and loss and understanding communication and behaviour.
9. PAMIS actively engages with local and national government to amplify the voices of those it supports, and influences policy and provision across Scotland.

b. A brief description of the group(s)/individuals which the person, organisation or body supports or represents.

10. 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.

11. 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 they 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.

12. People with PMLD clinically share a number of characteristics that make this term appropriate and does lead 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 that 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 valuable things 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.

13. The majority of people with profound and complex disabilities live at home with their parents. Research 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.

14. PAMIS supports over 850 families. The percentage of Children and Yong People in comparison to adults is dependent on each local authority area (e.g. In Tayside the makeup of the families PAMIS support is 60% have children with PMLD and 40% have adults with 70% living at home

and 30% living within supported accommodation or a care home. In North Lanarkshire there is a 50/50 split between children and adults. In South Lanarkshire 30% of our families have children with PMLD and 70% of families have adults. Within Lanarkshire as a whole nearly all of the people live in the family home. In all areas there will be limited numbers of older adults with PMLD but an increasing number are reaching adult hood and into their 30s.

c. A brief overview of any work of the person, organisation or body in supporting or representing the relevant group(s)/individuals between 1 January 2020 and 31 December 2022 as it relates to the response to the COVID-19 pandemic by the Scottish Government, where relevant.

15. At the start of the pandemic PAMIS adapted to the use of virtual technology and had grasped the use of Zoom. Within the first week they had had set up virtual full team meetings, supporting each other and clarifying how they would continue to support the families.

16. Within a couple of weeks using Zoom, and other electronic/virtual means, but mostly by phone, they had contacted all of their clients on database to update them about how PAMIS services were adapting to the lockdown, to check in on families and to listen to immediate concerns.

17. The daily team catch ups enabled staff to share/report issues which families were experiencing, such as a lack of PPE, not being on the shielding list etc. In some cases, families who had previously had 24/7 wrap around care, with some 5 or 6 people coming into their houses daily to support their relative, now had no one. That had an enormous impact.

18. Because PAMIS' community are small and because PAMIS reacted really quickly to lockdown, they were instantly able to feed what their families' experiences were into Scottish Government Learning Disability team. The civil servants rapidly set up a weekly leadership meeting, organised by NR supported by NR and attended by learning disability third sector leaders and key learning disability staff from within the Scottish Government.

19. PAMIS hosted webinars which had a UK wide and international reach. PAMIS developed a digital postural care learning resource, an area that they have been leading on for the past 15 years. Basically, for the PMLD group if their posture is not supported, they run the risk of becoming "windswept", where you develop a scoliosis, your internal organs are moved and forced out of place which can cause for example significant respiratory problems and can be fatal. Suddenly, this was an issue that impacted the general public, everybody realised they needed good posture to deal with the effects of Covid. PAMIS staff member, NR NR who led on their work related to this area, worked night and day to digitise our resource. This supported people to understand the importance of good posture and to be in the correct position to breathe

properly. PAMIS also turned our postural care training into an online programme for carers and families.

20. One of our key tools for our communities was our digital passport (https://pamis.org.uk/services/digital-passports) and its use to record various important pieces of medical and personal information regarding people with PMLD. It includes their likes, dislikes, such as music, films and games, but it also records specifics about the person's care, their postural requirements using photos and videos to explain these.

21. PAMIS shared this resource as far and wide as possible. It was decided morally that although prior to COVID this was a possible income resource, during COVID it was shared for free and PAMIS support others to use it.

22. Some families that PAMIS support struggled to access digital resources. PAMIS' own digital health lead acted quickly on accessing funds when they became available, using to secure not only devices, but also to fund the cost of internet subscriptions, distributing these benefits across our families.

23. PAMIS had many skilled people, including their Occupational therapy students on placement and they developed a whole range of online resources, to be used by parents and carers, wherever they may be. They had feedback that these resources were an absolute lifeline because it gave people appropriate, meaningful, evidence-based activities to do, often in the most trying circumstances of lockdown and wider isolation.

24. It was also difficult when the guidance kept changing. PAMIS didn't put the guidance on their website but directed families to the Scottish government guidance and the Scottish Commission for people with a learning disability (SCLD), The civil servants shared latest updates via emails which were sent through the family support directors to then share with families. It was tough to remember what was right or not and what had been said.

25. The Family Support Directors felt it was imperative to see families and families frequently asked if they could meet with them. Initially obviously this was in the garden but at times they needed closer support to manage for example online meetings when they were struggling with IT. There was also a real need to engage with families whose child was in transition to adult services, so PAMIS were keen to have restrictions governing this essential engagement reviewed as quickly as possible.

26. PAMIS also worked with a number of families who really struggled. Working with them staff undertook very stringent risk assessments so they could identify safe ways of engaging with them face to face.

27. PAMIS were also very vocal about the need for a family carer and/or known paid carers had to accompany a person with PMLD, regardless of their age, in ambulances, in A and E and within hospital.

28. PAMIS also campaigned for the Scottish Government to recognise family visitors to care homes and supported accommodation as members of staff, because they were providing a service. However, this was never acknowledged.

d. A brief overview of the key issues and impacts experienced by the group(s)/individuals which the person, organisation or body supports or represents, as a result of the COVID-19 pandemic in Scotland and the response by the Scottish Government. Please limit your response to a maximum of 5 pages at this stage.

29. The Inquiry is required to understand the characteristics, needs and priorities of people with PMLD in order to properly assess the pandemic's impact on them. Despite there being a wide range of disabilities within the group, the need for care on a 24/7 basis is universal: people need constant supervision and assistance, with things like posture, moving, transferring, toileting, and eating. People with PMLD experience an extensive range of medical and health issues which require constant monitoring and interventions. In `normal' times, there is a need for multi-agency input, to provide services such as physiotherapy, occupational therapy, speech, and language therapy — and of course, vital respite for the family carers, with day services and short-term residential placements. These services require to be co-ordinated and managed. Families are often essential care givers; part of the team involved in a person's care which can be provided within the family home, or in a residential or supported facility.

Impact of Restrictions

30. When lockdown restrictions commenced individuals with PMLD's entire routine was disrupted. It was clear the impact this had on individuals with PMLD who started withdrawing, becoming depressed and lethargic. People with PMLD don't always understand what change is and why it happens. It can often lead to distressed communication which challenges those caring for the person.

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32. For individuals with PMLD it is essential that they are engaged in physical and multisensory activity. For them, being trapped indoors was incredibly

difficult. It was extremely challenging to keep individuals with PMLD entertained and engaged without their usual schedule of activities and support. Many individuals whom PAMIS supports suffered tremendously as a result of losing most of their usual sensory input and activity; not being able to get out into the fresh air really affected them both physically and mentally.

33. Restrictions meant that individuals with PMLD were trapped indoors for large periods of time. This resulted in limited opportunity for movement and activity which caused weight increase, deterioration in mobility, change in body shape, decrease in range of movement as well as physical and mental wellbeing deterioration.

34. The Scottish Government and their civil servant team were really receptive to the issues created for the families PAMIS supports as a result of their guidance that only permitted outside exercise once a day. While the guidance was changed to create exceptions to this rule families that PAMIS supported experienced being challenged by members of the public, especially if they were seen out more than once per day having a walk. People in some communities were policing what they saw as infringements of the rules.

35. The requirement to shield significantly increased social isolation for individuals with PMLD, many who had to shield since the outbreak of the pandemic.

Impact on individuals residing in supported accommodation and care homes

36. The rules from Public Health Scotland stated that families could not visit those in care homes. Unfairly, people with profound and multiple learning disabilities living in supported accommodation, were also categorized alongside those living in a large predominantly elderly care home. The complete removal from family members, friends and allied health professionals from supported accommodation and care homes had a significant impact on individuals with PMLD.

37. The lack of access to their loved ones had a significant impact on individual's with PMLD's mental health and wellbeing. For a group of people who are unable to comprehend the reason their families are no longer visiting, this had a really depressive/negative impact. The lack of contact has meant in some cases that relationships have broken down and in the worst cases their loved one doesn't respond to them anymore. Families themselves were reporting to us that they were seeing a huge deterioration in their relative.

38. In addition, the alternative visiting restrictions introduced by the Scottish Government (Window visits, outdoor and indoor socially distanced visits) were completely inappropriate for individuals with PMLD. Many individuals with PMLD require communication through physical touch and therefore throughout the time period that alternative visiting arrangements were in

place all meaningful communication with their loved ones was removed. These visits often caused distress for individuals with PMLD as they did not understand why they required to be socially distanced and were unable to interact with their loved one.

39. Video calls were also inappropriate as individuals with PMLD often did not understand why their loved one was on screen or where their loved one's voice was coming from. It was also unsuitable for individuals who had hearing impairments and communication difficulties. These visiting arrangements prevented families from having a real relationship.

40. When indoor visiting was introduced the requirement to wear PPE also caused confusion and distress for many individuals with PMLD. There was no way to explain to individuals with PMLD why these masks were being worn. It also often resulted in individuals with PMLD not recognizing their family members.

41. Family carers for individuals with PMLD in care accommodation still play a significant role in their relative's physical, emotional and sensory care. This lack of involvement for many family carers was particularly frustrating and distressing as they had been accustomed to not only spending time with their family member but also supporting the care staff in the provision of care to their relatives. The role of family carers was disregarded by the Scottish Government's guidance. Family carers had always played a key role in the support team, and this was unilaterally withdrawn to the disadvantage of the individual, their family and the care team itself. As a result of this, PAMIS requested that the Scottish Government recognised family visitors as members of staff, because they were providing a service. However, this was never acknowledged.

42. One of the greatest sources of distress to family carers no longer able to see their family member was that they were likely to have spent a lifetime of caring for their loved one, even to the extent of keeping them alive. Those family members would have taken the utmost precautions to ensure that they did not endanger the wellbeing of their child or relative and will have continued to do so throughout the pandemic. They found the approach taken to be insulting, offensive and patronising as well as detrimental to their family member's wellbeing.

43. The unfortunate reality is that for many individuals with PLMD residing in supported accommodations or care homes the only level of engagement they received was when they are having their immediate personal care needs met, such as being fed or hygienic care.

44. This is not a criticism of care staff, they are not trained practitioners such as occupational therapists, clinical psychologists, learning disability nurses. But a lack of purposeful and meaningful activity and engagement can lead to depression and visiting family members ensured their relative received this. Paid care staff within the persons home were under a huge strain, suddenly providing all the care and activities without support from families and the wider team. They also had a significantly increased

workload because of the requirements of COVID resulting in a reduction in time available to provide meaningful activities to the people they were caring for. This was an isolating and emotional time for staff.Family members did not understand why they were not allowed to take the same precautions that staff members did to be near their loved one. Family members felt frustrated and helpless.

45. It was extremely difficult for family members to experience restrictions loosening around the country but for this not to be reflected within care homes and supported accommodation. It was also difficult for families when they witnessed different health boards taking a more relaxed view than their own in regard to restrictions.

46. Often the Scottish Government would announce a change to guidance, for example, allowing overnight visits, however, care homes and local public health departments would not allow this. It was also extremely frustrating for families to hear the Scottish Government announce a loosening of restrictions within care homes for this then not to happen. It was often felt that the guidance from the Scottish Government was ineffective as it could be ignored.

47. Due to the restrictions some families decided to move their loved one out of a care home/ supported accommodation. This meant that they had to care for their loved one, including carrying out physical tasks (showering, changing, moving and handling) 24/7 without any support in place.

Removal of Support for Family Carers

48. Many people with PMLD are cared for by their families at home but with support from services such as schools(for children) day services (for adults), respite, short breaks, personal assistants and other family members. When this support was lost it led to diminishing skills for the person with PMLD, increased anxiety, social isolation and loneliness for the person with PMLD and for the family carers

49. At the start of the initial lockdown, without warning families found that they had no support at all. These families were responsible for 24/7 care with nothing to alleviate that, no one at all to come and help, no one they could call and no indication as to how long this might last for. Some people with PMLD have very broken sleep. They and their families were at the end of their tether with no one to talk to who could help or support and no light at the end of the tunnel. In some cases, people with PMLD were literally climbing and punching the walls. They could not possibly understand the changes in their circumstances caused by Covid and could not communicate their fears, anxieties or physical pain.

50. The removal of this significant support resulted in a more intensive role required of parent carers. Some family members reported being forced to leave their employment as they were unable to work whilst also providing this higher level of care for their loved ones. It also resulted in an increase

inrequests from parents for their children/relative to go into residential/supported care. Before Covid, their imperative was to keep their relative at home. But parents were exhausted, many felt utterly abandoned by all their services, treated very unfairly by Social Work Departments, remaining almost invisible and left behind as services resumed and the rest of the world got on with living. There is such a short supply of appropriate accommodation, with properly trained staff, that some Social Work Departments are now trying to place people with PMLD into older people care homes, which is wholly inappropriate and the skills set required to work with people with PMLD are different.

51. Day services were slow to reopen. If they reopened at all, this was at a significantly reduced capacity, and it was not clear what the criteria was for prioritising places. Many staff hade been redeployed, and so were not thereafter available to return to their pre-pandemic role. It appeared that there was no appreciation of the vital nature of the day services. The Scottish Government commissioned an audit of adult day and respite services across all Scotland's local authorities in May 2022. At the time of the survey, only 48.7% of day services were fully open, with 38.4% partially open or at reduced capacity and 11.8% closed. For respite services, 68.3% were open, 16.9% were partially open or at reduced capacity, and 14.1% were closed. By November 2022, day services were at 75% of capacity and respite services at 68% of capacity. The cuts in service provision have resulted in significant financial burdens for families.

52. For family carers the impact of the pandemic on their mental wellbeing was serious. They were invisible and there were wholesale negative impacts caused by the withdrawal of services and the increasingly insensitive approach adopted by care services. The reality is that family and paid carers were, emotionally, on their knees, asking for help and not getting anything and not knowing where to turn.

53. Family members were concerned about the lack of appropriate support and contingency planning for their relative should they become ill with COVID. This reflected the reducing opportunities, pre-COVID, for families and people with learning disabilities to make plans for their future or about moving from the family home.

54. The Pandemic also exacerbated the concerns faces by aging carers. People with PMLD are now living longer, but this means that many of their parents/ family carers are still occupying care positions into old age. Many may have struggled with their own health concerns while carrying out their caring responsibilities. Again, during the pandemic, having to provide all care over an extended period of time when dealing with their own health issues will have been extremely challenging for them.

55. During the Pandemic there was a lack of sufficient support for families who had babies with PMLD.

56. The increase in people caring for those with PMLD having suicidal thoughts and suffering debilitating mental health issues is of tremendous concern. This has always been a reality for PAMIS families but has been significantly exacerbated by Covid.

<u>Impact of school closures</u>

57. Many children with PMLD require one-to-one support and intensive care all the time. When schools closed parents provided this support while also juggling all the other things they would have to do in the home and potentially supporting other children. Some children were eventually able to access school albeit at reduced hours. The closure of schools will have undoubtably impacted their ongoing development.

58. Families reported the feeling of guilt that the other children in the house, the siblings of the child with PMLD, were often left to get on with things themselves. It was impossible to support a child with very complex needs and provide input into the education and support for the other child/children. For the sibling themselves there was also increased anxiety about COVID and bringing it into the home. This was apparent when schools returned and siblings worried about the risk of catching Covid and then infecting their brother or sister with the potential life threatening consequences. Equally not returning to school or seeing peers impacted on the wellbeing of the sibling For older siblings not living with their brother or sister there was forced separation for prolonged periods which impacted on both parties.

59. The closure of schools had a huge impact on children's physical wellbeing. They did not have access to physical aids like hoists or standing frames so they couldn't continue their exercises and many of them deteriorated physically.

60. For children who didn't have learning disabilities, lessons were being provided to them by their teachers to complete at home. There seemed to be a lack of support for children with PMLD being schooled at home. In a special school, a lot of the education is based on physical interaction, touch, eye contact, and multi-sensory experiences that were difficult to replicate online.

61. As a result of school closures, families reported to PAMIS that their young people lost communication skills. These children and young people lost skills which had taken their lifetime to develop.

62. Many families highlighted that they could see that their children were depressed, appeared lost and were isolated.

63. The loss of routine was equally detrimental to the young people. While they have limited capacity to understand the structure of their day, the repetition is really important for them to understand what's going on. And again, the development of these routines had taken many years to embed.

64. PAMIS were aware of only a few families being provided priority places in hub schools for the children they supported and this appeared to be for frontline workers rather than for the child's benefit.

65. PAMIS are aware that a few families requested their child be able to resit a year of school to make up for the lost time. This was refused and the perception was that the local authority did not appreciate the value of education for individuals with PMLD. It felt as though because they were not sitting exams, they did not matter.

<u>Impact on Transitions</u>

66. PAMIS families experienced significant difficulty in young people with PMLD being effectively transitioned from children to adult services during the Pandemic. When children with PMLD are in education, they usually have access to physiotherapy, hydrotherapy, speech and language therapy, occupational therapy and other relevant additional support. However, as soon as they leave children's services and transfer over to adult services, the young person's day will look quite different. This transition period is stressful and COVID measurements undoubtably increased the stress. Transitions onto adult services were incredibly difficult because no meetings were taking place. Families would usually spend time looking at options for adult services for their children, but they couldn't do that during the pandemic. That preparation did not happen so transitions out of children's services into adult services became very challenging.

67. The necessary communication between adult and child services was disrupted. Ideally, when planning a transition, the needs of the person with PMLD and resources available will be considered, discussed and negotiated. However, Covid measures meant services were closed with staff redeployed. Disruption of normal practice prolonged and complicated an already challenging process.

68. Transitions for children with PMLD also include a transition from paediatric to adult health services. This requires health services such as the Allied Health professions to carry out an assessment of needs, complete reports and provide these to the new adult service. Some PAMIS families experienced that during Covid these reports were lost and not processed properly. This resulted in adequate supports not being in place. Once families discovered this, they had to restart the process of referring their child to adult care which resulted in them returning to the back of all the relevant waiting

lists.When a young person transitions to adult care, they need an adult social worker to administer and agree the budget in order to get care packages.There was a shortage of adult social workers, and the meetings weren't happening. This meant some young people had to leave school with absolutely nothing for them to move on to.

69. Structure is very important for people with PMLD so having the opportunity to move straight from school to a day service is really beneficial. Few families had the option to transition their child straight from school to the day service and lost that routine. This can set them back years and sometimes they never get back into that routine.

70. Many young people were left in limbo with a lack of support. Young people going through transition were further disadvantaged at a point in their life journey that is difficult at the best of times.

71. Transitions from primary school to secondary school were also difficult because families couldn't meet their child's new teachers or visit the new school. The preparation and handing over of information broke down.

Lack of access to Medical Services

72. For individuals with PMLD there was a lack of access to medical care, including GP appointments, routine hospital appointments, and the availability of medication. Families often experienced regular medical appointments, health checks and medication reviews being cancelled or postponed. The lack of access to routine appointments resulted in health issues not being identified or treated. Individuals with PMLD often experienced their medical procedures being postponed as they were not prioritised by the NHS.

73. The postponing of surgeries had irreversible consequences for many. One individual with PMLD had a curvature in their spine that required spinal surgery. The spinal surgery didn't go ahead because of COVID. Sadly, the curvature of the spine progressed to a point where it was inoperable, and the impact of that surgery not being received was catastrophic and resulted in premature death because the individual's internal organs were compacted which affected his breathing, eating and drinking. His death was a direct result of the damage to his organs.

74. The introduction of remote GP consultations were not appropriate for individuals with PMLD for whom physical examinations are crucial to monitor their health conditions and to diagnose medical issues.

75. During the Pandemic many individuals with PMLD experienced changes to their size and weight as a result of significantly reduced physical activity. This had implications for medical and therapeutic equipment and for many there was no access to appointments for equipment review.

76. There is a lack of acknowledgement of the impact that the lack of treatment throughout Covid had on individuals with PMLD. Often health professionals contribute these impacts to the individual's PMLD rather than acknowledging the worsening of conditions as a result of the lack of treatment and intervention during the Pandemic. This results in individuals not being provided with the care and treatment they require.

Removal of allied health professionals

77. One of the greatest concerns for PAMIS during the pandemic was that highly skilled Allied Health Professionals, were being redeployed. The support these professionals afford was invaluable. Taking it, all away very quickly had a profound negative impact on individuals with PMLD's overall health and wellbeing.

78. Individuals with PMLD rely on people to support them 24/7, many require support to mobilise/move, many require equipment, access to hydrotherapy etc. All the services stopped, with Allied Health Professionals dispersed elsewhere, day services closed, hydrotherapy services closed, the whole overview and delivery of our group's physical health, care and wellbeing was halted.

79. Many young people with PMLD also access a significant number of their healthcare services and interventions through their school. As a result, when schools closed access to integrated healthcare services just stopped.

80. Families were reporting to PAMIS that the skills their relative had developed were being lost and families feared that they might not regain them. Motor skills, mobility, speech, engagement are skills and abilities that can take years to develop and are achieved only because of focused, ongoing interventions provided by families and carers supported by a range of co-ordinated allied health professionals and social care. The withdrawal of these services meant that individuals with PMLD's physical health regressed and again families are concerned that this might impact their future wellbeing.

81. Many individuals with PMLD experienced significant physical deterioration. Much of this deterioration was as a result of muscle tightening, which can happen when an individual is in the same position repeatedly. This deterioration can manifest as contractures, wrists will turn in on themselves and arms will become really tight. Hands might stay very close to the face, making it hard to move the arms away. If sitting a lot, knees will contract.

82. A key concern with limited or no access to Allied Health Care Practitioners was the impact on the person with PMLD's posture. Postural care is not intuitive and is sometimes out with families' knowledge. PAMIS is heavily involved in the promotion of postural care which prevents or minimizes body distortion, and without which can lead to premature death. This is ordinarily monitored by physiotherapists, occupational therapists, paediatricians and the wider clinical community.

88. The wholesale withdrawal of Allied Health Professions and other health services overnight meant that people who were already deemed to be at high risk of scoliosis, just disappeared from routine medical interventions. One PAMIS family experienced devastating postural deterioration in their child, displacing all internal organs to such a severe extent that they died.

89. This person did not die of Covid. This person died because of Covid. When all the services required by an incredibly vulnerable group are withdrawn, completely, the impacts can be devastating. In this case the child's death was avoidable and unnecessary, and it seems likely that they would have been in considerable pain during the last 2 years of their life as their body shape altered. This would have been avoidable if they had received the medical care that they evidently desperately needed but also if they had received an appropriately adapted wheelchair for their change in size as they grew older.

90. One of PAMIS' key concerns now is how will the Allied Health Professionals catch up with the extended period of no engagement with this group and their complex needs. The impacts are already profound and will require more intense medical and social care interventions as the years go on.

91. What is clear is that there is a lack of staff, people are retiring, or they have moved on. Employing staff with appropriate skills is very challenging, so the impact of COVID pandemic on this group's physical health is nowhere near being dealt with. The impacts are still being felt.

<u>Impact of Frailty Scale</u>

92. A highly stressful period for PAMIS families was the introduction of the Clinical Frailty Scale, which was intended to assist medics with decisions about who could or should, be treated during the Pandemic.

93. As an organisation, PAMIS already knew that people would make judgments about our group, about the quality of their lives and about how valued they were.

94. This proposal about the scale sent absolute panic through PAMIS' community One parent told PAMIS about how she had to race down the motorway to get to the hospital where her child had been taken because they thought the hospital would make a judgment about the quality of their life and not offer treatment.This rationale of judging another's quality of life is, according to a student that PAMIS had on placement, backed up in medical journals. However, this physio student concluded after a practice placement with PAMIS that if medics just concentrate o quantitative data, as opposed to qualitative data, provided by families and their experiences, there will always be a perception about our group's quality of life as a factor in whether medics pursue interventions or not.

95. This scale was declined in Scotland after PAMIS and other third sector

organisations from Learning Disability groups, made successful interventions to Scottish Government, but the reality was that some people did still think that these decisions were applicable; with no knowledge of the positive lives people with PMLD have they were obviously making a judgement - "what quality of life do they have?". It really terrified and traumatised families.

96. Pre COVID-19 PAMIS heard of instances where the person's quality of life was not valued, where there would be Do Not Resuscitate conversations held that seemed inappropriate. Where there was treatment carried out or not carried out, that felt it went against what families wanted staff to do. Families were also worried the person being cared for might be neglected, if the family carer wasn't present 24/7. They would do whatever they could at home to avoid having to go to hospital, even before COVID-19.

Impact of restrictions with hospital

97. PAMIS were also very vocal about the need for a family carer and/or known paid carers to accompany a person with PMLD, regardless of their age, in ambulances, in A and E and within hospital. One parent highlighted that an infant would not be expected to be left without their parent so why would you expect someone with a developmental level of a very young child and who cannot speak for themselves, who will most likely be terrified of what's going on, will react in a way that will most likely be interpreted as disruptive and could cause damage to themselves, others and the environment, to be unaccompanied by a known carer?

98. The reality is, that the person with PMLD cannot explain what is wrong and they need experts in their communication to interpret as well as to ensure they are not traumatised. An expert carer will assist in calming and reassuring them, assist in the assessment and treatment and ensure the person with PMLD is safe. PAMIS have been working on this pathway for a few years.

99. Even though PAMIS had this agreed as policy with the Scottish Government, it did not always filter down to the NHS and HSCPs. PAMIS frequently received calls from families during Covid to say they were struggling to get access atthe hospital who were trying to exclude them, even though the parent was highlighting to the hospital staff that the person with PMLD would need them to deal with the complexity of their child's overall care needs.

100. This is more pronounced when the individual is an adult. Paediatric services are more understanding and aware of these complex needs, but not so much when the child becomes an adult and is no longer in in paediatric services.

101. Health and Social Care must work together so that there is a hospital

pathway that allows paid carers to go into hospital. One of the civil servants in the Learning Disability team at the Scottish Government worked with Pat Graham, a family carer who had raised this issue, and PAMIS. This led to directive addressed to Local Authority Chief Executives, NHS Territorial Board Chief Executives, HSCP Chief Officers, Chief Social Work Officers, Directors of Public Health, Social Work Scotland, COSLA, Care Inspectorate, Coalition of Care and Support Providers in Scotland and National Carer Organisations from the then Cabinet Secretary for Health and Sport Jeane Freeman to endorse that paid and family carers needed to accompany people with PMLD within acute hospital settings (Letter dated 17th November 2020). However, this still made no difference. PAMIS representatives met with HSCP Chief Officers, and they admitted that until PAMIS had presented the narrative about the letter, they hadn't understood why the letter had been sent and not understood the impacts and realities facing our group, all of whom have a range of complex needs, when going into hospital.

102. This issue precedes the pandemic and is still an ongoing battle. Social and health care services are not yet back to pre-covid levels. When you couple this with the array of negative impacts upon our group, there is a greater likelihood that individuals with PMLD will require hospitalisation, more frequently. It is essential for their wellbeing that carers who know the individual are allowed to accompany them to ensure that they can support NHS staff who are not trained to understand individual complex needs, communication and behaviours.

Difficulty with Equipment

103. During the Pandemic there was also an issue with people with PMLD not getting replacement equipment, missing out on wheelchair fittings and consequently left in ones that were incorrect.

104. PAMIS heard from families about equipment being sent out with little or no instruction and in some cases equipment was inappropriate regarding size and ill fitting. PAMIS supported some families to try to access proper equipment recognising the significant risks from for example postural deterioration and, if left untreated, the fatal consequences. PAMIS also

recognised that without appropriate equipment to move the person with PMLD the relative/family carer was at risk of injury.

105. During the pandemic some people with PMLD put on weight due to the lack of physical activity or outgrew their equipment and family carers were having to do moving and handling procedures that were inappropriate but with no choice if their relative was to be cared for. PAMIS ran online workshops with experienced consultants to address the issues and to provide support in safe handling and moving processes. Families were grateful but some of the things they highlighted were really difficult and it was appalling that families were left in that situation.

106. PAMIS were aware that wheelchair users who were going through adolescence during the pandemic were put at risk because wheelchairs were not replaced to ensure that they fitted properly and provided best support. This is a real risk of postural deterioration, pain and discomfort and the loss of broader physical skills which will have taken years to develop. It is important to note that many people with PMLD will be wheelchair users constantly from the time they get up in the morning until they go to bed at night so if they wheelchair no longer fits then the individual is exposed to that incorrect body position for many hours a day.

Issues with Self Directed Support

107. Significant issues were experienced during the Pandemic by individuals with PMLD that received a Self-Directed Support (SDS) budget, under option one of the SDS choices. SDS is supposed to enable more choice and control over the way care is delivered, where it is delivered, and by whom.

108. However, during the pandemic, access to services were stopped and the money allocated to provide the person's care and services went unused. Post-COVID, some local authorities sent written demands that any allocated money unused, due to COVID measures, should be returned to the local authority. This was considered unfair.

109. Some families who hired their own paid personal assistants to come into their home and help support the person with PMLD, continued to pay the personal assistants even though their personal assistants were now unable to deliver that care. Family carers were afraid their personal assistants would leave. In situations where paid assistants coming into the family home were provided by a care organisation and not hired directly by the family, these paid care workers were often redeployed. This meant that some families went from having fully trained staff with the knowledge and understanding to care for their relative, to no, outside of family, support. This was worrying, especially when experience knowledge and understanding of the person is crucial to appropriately and safely care for a person with PMLD

110. PAMIS families also reported ill-informed decisions being made by social care budget holders in relation to Self-directed support funds. PAMIS supported a family to challenge a decision after letters from a young person's GP and physiotherapist had outlined the negative impacts of the closure of the local hydrotherapy treatment centre on their child's health, and that a small jacuzzi to be placed in their summerhouse would prevent their health deteriorating further. There was money left within the persons Self Directed Support funding, because of lack of ability to acquire services over the pandemic and the health team agreed with the parents that this was a useful way to support health and wellbeing in the absence of any hydrotherapy sessions.

111. Despite the cost being equitable, a social care panel dictated that this was not an appropriate way to use the additional self-directed funding and declined it. This was despite supporting written evidence from medical care services concerning the obvious deterioration in the young person's physical health and mobility and the national guidance about alternative use of the funds because of the pandemic.

112. In addition, despite explicit Scottish Government instruction that care packages would not be reviewed or reduced during the pandemic period, PAMIS heard from families who were visited by Social Work, who stated that it was not a formal review, yet, upon completion decided to reduce the funding families received. This was because the families were perceived as managing to deliver the care themselves.

113. With the removal and reduction of services during the pandemic, many families had uncertainty about how they could spend their budgets during the pandemic, if they could at all, many had no access or extremely limited access to a social worker who could confirm that a budget spend was within the boundaries or the more relaxed boundaries that were implemented. It left uncertainty. If families took the risk and spent money on items or breaks that weren't included in the young person's outcome based support plan there was always the risk at a later date that they would be required to pay this back and many families wouldn't have the financial means to do this.

Impacts on PAMIS staff

114. There was huge trauma for PAMIS staff, caused by having to hit the ground running, to provide support to families where all other services had disappeared.

115. Staff also had to start working from home immediately without access to the facilities and colleagues in their workplaces. Staff took this to heart. They

often felt inadequate because they were hearing directly all about the increasing pressures that families were having to deal with and their consequential distress. Staff felt an overwhelming sense of responsibility to do what they could to fill the gaps in services. The pandemic increased the workload for staff, who felt they were continually meeting brick walls. Local Authorities, especially Social Work departments, became increasingly difficult to contact, PAMIS staff really struggled to benefit the families they supported in the way they had prior to the pandemic.

e. A list of any articles or reports that the person, organisation or body, or the groups(s)/individuals they represent, have published or contributed to, and/or a list of any written or oral evidence they have previously given to any body (for example to Scottish Parliamentary Select Committees) regarding the impact on the group(s)/individuals they support or represent, as a result of the COVID-19 pandemic in Scotland and the response by the Scottish Government.

Document	Date	Information	Link (If applicable)
Your posture matters A strategic approach to taking care of it together	2021	PAMIS were co-authors of this having campaigned for a strategy over many years. Family carers were part of the co-authoring and were instrumental in providing the examples and stories to highlight the need and benefit. PAMIS supported focus groups with families and practitioners to develop the recommendations within the strategy. We also supported the launch of the strategy and ongoing awareness raising. We led the development of training and delivered training with family carers as co-trainers with practitioners. This work has been a part of our workplan for 15 plus	https://learn.nes.nhs.scot/60813#

		years and we continue to lead the national reference group	
Your posture matters Let's take care of it together Executive Summary	2021	PAMIS co-authored this with the Scottish government children and young people AHP lead. Again family carers were part of the team.	https://learn.nes.nhs.scot/60813#
Your posture matters Let's take care of it together Learning Framework	2021	As above	https://learn.nes.nhs.scot/60813#
Response to the Education and Skills Committee which, among other matters	15 May 2020	PAMIS contributed to this report 2020 by the Health and Social Care Alliance (the Alliance) which, among other matters, highlighted the issues for children with PMLD when schools were closed	
Building Blocks: Exploring the barriers and facilitators to early learning and childcare provision for children with learning disabilities in Scotland - The Scottish Commission for People with Learning Disabilities	March 2022	Contributed to by Jenny Miller in her capacity as SCLD trustee member but also on behalf of PAMIS community	
OVERVIEW OF THE PROVISION IN SCOTLAND OF EARLY	March 2023	Contributed to by Jenny Miller in her capacity as SCLD	

LEARNING AND CHILDCARE FOR CHILDREN WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES WITH A LIFE-LIMITING OR LIFE THREATENING CONDITION		trustee member and PAMIS CEO	
PAMIS final report on the Scottish Government funded PAMIS My Voice, My Choice Project	November 2022		
Feedback provided to Education, Social Work and Young People Strategic Group.	03rd Sept 2020	A small subgroup of the DCYPAG, including PAMIS, were asked in September 2020 to prepare a presentation on some of the specific immediate issues/challenges faced by the communities PAMIS supported in terms of children and young people. There were many challenges, but at that time PAMIS focused on the immediate issue in terms of support for education. This was fed into the Education, Social Work and Young People Strategic Group. This is a group that was set up prior	

		to the pandemic but had a focus on COVID during the pandemic. The information shared came directly from the feedback from PAMIS family support directors who were working with the families.	
Email from Jenny Miller to Children in Scotland and copying in NR (Learning Disability Policy Manager at Scottish Government) noting various queries PAMIS would like to raise on behalf of family carers to Cross-Party Group on Children and Young People	25th May 2020	PAMIS is a member of the Cross-Party Group on Children and Young People. On the 25th May PAMIS emailed the group a list of concerns which had been raised with us by family carers of young people with PMLD. These matters related to transitions, health, and wellbeing, easing lockdown-route map, and respite and support. PAMIS do not recall receiving a response to these concerns	
Email from Jenny Miller to Children in Scotland noting one question to be asked of Minister for Children and Young People, Maree Todd, Minister for Further Education, Higher Education and Science,	27th May 2020		

Richard Lochhead and Minister for Older People and Equalities, Christina McKelvie			
The Coronavirus and people with learning disabilities survey		Warwick University led the research working with other universities across the UK. In Scotland, Glasgow University was feeding into the UK data. The Scottish Commission for Learning Disability (SCLD) was the link organisation for people with learning disabilities and PAMIS was the key partner in Scotland supporting the those with PMLD and their family carers. We were part of the research advisory group contributing to the design of the questionnaires for each phase of the project, ensuring that families were involved, disseminating results and supporting the production of the film We also supported the development of the recommendations and contributed to the policy round table with the Scottish government. We also co-presented at the learning disability Cross party group to	Policy Brief https://www.scld.org.uk/wp-content/uploads/2022/01/Coronavirus-and-people-with-learning-disabilities_Policy-brief_15.03.22.pdf Link to wave 1 report https://warwick.ac.uk/fac/soc/cidd/covid19-learningdisability/results/wave1results/fullreport/coronavirus_and_people_with_learning_disabilities_study_wave_1_full_report_v1.0_final.pdf Link to wave 2 briefing on results https://warwick.ac.uk/fac/soc/cidd/covid19-learningdisability/results/wave2results/briefing_-_access_to_health_and_social_care_services_wave_2_-_june_2021_v2.pdf Link to wave 3 results https://warwick.ac.uk/fac/soc/cidd/covid19-learningdisability/results/wave3results/coronavirus_and_people_with_learning_disabilities_study_wave_3_full_report_v1.0_final.pdf

		question what progress had been made with the recommendations. (June 2023)	Link to wave 4 results https://warwick.ac.uk/fac/soc/cidd/covid19-learningdisability/results/wave4finalreports/coronavirus_and_people_with_learning_disabilities_study_wave_4_full_report_final.pdf
Experiences of UK and Irish family carers of people with profound and multiple intellectual disabilities during the COVID-19 pandemic	11 Dec 2023	PAMIS was identified as an appropriate organisation to assist in reaching such family carers in Scotland. The research team sought to explore the experiences of family carers of people with profound and multiple intellectual disabilities during the COVID-19 pandemic and understand what the longer-term impact might be on their lives. An in-depth view of family carer's experience provided a rich understanding of the challenges these family carers faced at the time.	https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-023-17432-7
Equalities, Human Rights and Justice Committee- Women's unfair responsibility for unpaid care and domestic work Official Report	8th March 2022		Meeting of the Parliament: ehrcj/08/03/2022 | Scottish Parliament Website

Equalities, Human Rights and Justice Committee- Women's unfair responsibility for unpaid care and domestic work Transcript of talk	8th March 2022		
The Alliance Report of third sector responses to self-assessment tool	Oct 2021		
Response to Finance and Public Affairs Committee consultation: Scotland's public finances in 2022-23 and the impact of Covid	Aug 2021		
Glasgow University Event Transcript - The pandemic and lessons for policy		NR the Principal Investigator on the research, focuses on recommendations for policy. These recommendations come directly from disabled people and disabled people's organisations – including PAMIS- and reflect specific ideas about what needs to be changed for the future.	Link to NR NR presentation London School of Hygiene & Tropical Medicine

f. The view of the person, organisation or body as to whether the group(s)/individuals they support or represent were adequately considered when decisions about the response to the COVID-19 pandemic were made by the Scottish Government.

Scottish Government Guidance for Care Homes and Supported Accommodation

116. The Scottish Government exercised their devolved powers in respect of Public Health to issue guidance and direction to every area of our lives. However, the Scottish Government abrogated their responsibilities in relation to care homes and supported accommodation. The lack of guidance from the Scottish Government left local public health and care accommodations to make their own rules and to make their own interpretations of the guidance. This resulted in differing consequences and impacts for individuals in different local authority areas. In addition to differences in approaches between care accommodations within the same local authority. This resulted in a complete post code lottery of care.

117. Throughout the pandemic individuals in care homes and supported accommodation did not benefit from easing of restrictions that the rest of society benefitted from. The restrictions for the rest of society ebbed and flowed depending on risk levels whereas care homes and supported accommodations remained locked down with significant restrictions

118. There was an issue with the initial lack of clarity about the difference in guidance required for care homes and for other accommodation models such as supported housing. At the beginning our family carers who had relatives in supported housing were told by their providers that they were following the same rules as Care Homes but in fact these should have been seen as private dwellings. In reality this meant that families were deprived unnecessarily in seeing their relative and, for some, up to 18 months of separation.

119. Both families with relatives with PMLD in care homes and supported accommodations were requesting a positive message and the easing of restrictions which led to the Scottish Government's Open with Care guidance. However, despite families' interventions with the Scottish Government, their Open with Care only applied to Care Homes. This meant that while Individuals in Care Homes benefitted from the clarity and freedoms introduced within this guidance individuals in supported accommodation did not.

120. The Scottish Government provided significant discretion to public health to put in place guidance and restrictions. This meant that each public health team within each of the 14 health boards took a differing approach. When PAMIS would contact public health in relation to implementation of guidance, their advice would depend on the individual that picked up the call.

121. PAMIS wrote a paper to the Scottish Government explaining the disparities across the country regarding visits into our groups' care and shared accommodation. This outlined the risk assessment process, and evidenced instances where these risk assessments had been developed, agreed and were now being used with care providers because they themselves recognised the really detrimental effect that isolation was having on the individuals with PMLD. The paper also explained that when using these risk assessments to facilitate visits into care/supported living settings and allowing people with PMLD to enjoy home visits, staff could clearly see the positive difference on the overall wellbeing of the person. It pointed out the work which had been done in Canada to facilitate such visits; where relatives were being viewed as core/essential staff, enabled relatives into the care home environment. However, despite the support which PAMIS received and the very good support from civil servants who really understood the issues and concerns, the issue was not overcome.

122. Despite the Scottish Government publishing guidance about using risk assessments, how to conduct these in the context of identifying and managing risks associated with care home/residential care/supported living visits, these guidelines were not followed at a local level. So, despite the Scottish Government really pushing this good practice, it was mostly not permitted by Health and Care Partnerships in most local authority areas.

Lack of Specific guidance

123. PAMIS received constant, ongoing feedback from families throughout the pandemic in relation to the guidance published by the Scottish Government. The updates from Westminster and Holyrood on shielding, testing, PPE, vaccinations were not applying to our families. The daily briefings were for the mainstream population and were not for people with PMLD or their families. The practical application of guidance wasn't working for our group the way that it was being suggested it would.

Care Packages

124. Despite Scottish Government guidance that care packages would not be removed, Social Work departments acted in direct contravention of that guidance and reduced funding which impacted on the services that could be purchased.

125. PAMIS fed this back into their Scottish Government network but, as with a great many other issues surrounding government guidance, local authorities ignored this altogether and some of the officials PAMIS worked with were struggling to have their and our voices heard in the wider government and with local authorities. There was absolutely no accountability put upon local authorities to uphold and use that central government guidance. Some of this guidance had been developed by sharing good practice from across the country with central government divisions to formulate reasonable, practicable processes.

Reopening of Respite services

126. From March 2020 to Spring 2021 respite services were closed. They only started to open again in Spring 2021. This was despite the Scottish Government stating early in the Pandemic when communities were reopening that one of their key objectives was to reopen day services and respite services for the most vulnerable groups.

127. A very small number of day services remained open throughout Covid, operating a restricted operational model. However, it was clear that the majority of Local Authority areas closed and failed to reopen.

128. When day services started opening up in Spring 2021 there were policies that were put in place in relation to testing before families were able to access this support. The policy was that the person with PMLD who was to access respite had to have a negative PCR test within 48 hours before the respite was due to begin. This presented several practical problems.

129. While families agreed with the policy of testing, this excluded many from accessing services as testing would too traumatic and their sons/daughters would not be able to tolerate this.

130. Families were put under a significant amount of pressure to get the test back within this 48-hour window. Often the test result would not be available after 48 hours, particularly if it was a Monday or a Tuesday because it was slower at the weekends. This meant that families would lose their respite completely.

131. There was a time when families were unable to access PCR test easily and there was no support from the respite centres to do this. There were anxieties about how to get a PCR test, how to get the results back in 48 hours. Different families have different stories about how they had to access the PCR tests, with some having to resort to paying for this privately. At £80 a time this was not an option that was available to everyone.

132. Once services began to open up, the allocation of these seems sporadic with no set criteria of who was entitled to access. In addition, these services were operating at a reduced capacity. There was confusion around how you could access these services and how long for. Families weren't aware of the processes or risk assessments that were carried out to determine who could access the limited services available.

Shielding

133. Scottish Government restrictions in relation to shielding demonstrated paternalistic practices with a focus on protection which lacked involvement of individuals and family in emergency planning and risk assessment. Families are experts in risk assessment as they have been required to carry them out for the entirety of their loved ones' lives.

134. Many of our families also experienced being missed off of the shielding list

due to their GP surgery not having accurate records. This meant that they were ineligible to access support initiatives, such as assistance with shopping.

Vaccination Process

135. Individuals with PMLD were not on the initial priority list for vaccinations due to their main diagnosis being a learning disability. PAMIS approached the Scottish Government in relation to this and they stated that if individual's GP would not agree to them receiving the vaccines then the Individuals with PMLD's family should contact the health board. This was an additional burden for families in addition to their increased caring responsibilities at this time.

136. Information on the vaccine process was poorly communicated which resulted in apprehension for individuals with PMLD and their families in relation to attending large vaccination centres. It was unclear whether reasonable adjustments would be made.

137. Individual arrangements for the vaccine largely depended on the individual's health board and GP. This resulted in no uniformed approach in relation to whether individuals with PMLD would be required to attend a vaccination centre or receive their vaccination at home. There was also a lack of coordination for family carers being vaccinated at the same time. This was a particular problem when carers were young which meant they were low down on the priority list for vaccinations.

Lack of consideration of Third Sector Organisations

138. The Scottish Government guidance and policies lacked an understanding of the role the third sector played. This resulted in uncertainty for PAMIS staff in relation to where they could access PPE from. PAMIS staff also were unable to access testing kits when they were carrying out activities due to not being a registered care provider or carrying out personal care.

139. The instruction was that the volunteers working with PAMIS could be tested, but not paid staff. Staff were more consistently involved with the families and in terms of engaging and communicating would often require to be up close to the person with PMLD. Access to tests was a tick box exercise and despite PAMIS explaining their role and rationalising the reasons they should receive the testing kits to mitigate cross contamination risks, they were not provided.

PPE

140. Despite clear national guidance on required PPE, by the time it filtered out to various authority areas it was interpreted differently. Some would consider

the risks associated with our group of people and provide families and their staff with adequate PPE. Others, though, just ticked boxes and did not use common sense.

141. Some families had to pay for their own PPE and this cost could not be recovered through their health budget.

g. Whether the person, organisation or body, or the groups(s)/individuals they support or represent, engaged with the Scottish Government when the Scottish Government was making decisions about its response to the COVID- 19 pandemic. Please provide a list of any such correspondence or meetings with the Scottish Government, including the dates, to whom the correspondence was addressed or with whom the meetings were held, and any response received from the Scottish Government.

Meetings

- PAMIS were part of the Disabled Children and Young People Advisory Group (DCYPAG) which is a Scottish Government group that involves third sector organisations. It had been a longstanding group prior to COVID but became a really useful source of intelligence for the government during the pandemic as well as a support group for all the organisations to share practice and experience and solutions. A small subgroup of the DCYPAG, including PAMIS, were asked in September 2020 to prepare a presentation on some of the specific immediate issues/challenges faced by the communities PAMIS supported in terms of children and young people. This was fed into the Education, Social Work and Young People Strategic Group.
- PAMIS were connected with the GIRFEC Advisory Group which is run by the Alliance. Another long-established group prior to the pandemic and with benefits as above during COVID.
- PAMIS is a member of various cross party groups including: learning disabilities, physical disability, carers, social work, epilepsy, children and young people, Changing Places Toilet, government of carers, palliative care.
- Member of the Children's Sector Strategic and Policy Forum- longstanding group but met during COVID

- Children with exceptional health needs (CEN) network – longstanding group but met during COVID
- Covid Highest Risk Meeting 6th May 2022
- Open With Care Advisory group and the Care home/supported accommodation (CPAG) Scottish Government Group and subgroup for Anne's Law and The Care Home Standards.
- Postural Care strategy – PAMIS continuing to co-chair the national group that will support the delivery of this. The lead has also liaised with Professional Advisor from Scottish Government over the ongoing Guidance for Equipment and Adaptation
- PAMIS were also part of the Scottish Government Learning Disability Leadership group which in the initial stages of the pandemic met on a weekly basis to share information from the Scottish Government and from PAMIS as organisations working with specific groups of people with PMLD
- Scottish Government Keys to Life Leadership hub, providing intelligence and support for COVID 19 responses and recovery and transformational plan
- Scottish Commission for Learning Disabilities Evidence into Practice Board
- Self-Directed Support Scotland Management Committee
- Inspiring Scotland/SG Learning Disability Portfolio
- Scottish Learning Disability Nurse leads group
- Excellence in care national group
- Scottish Learning Disability Nurse Education Group
- UK Changing Places Toilet Consortium
- Transport Scotland Accessible Travel Advisory group
- NMAHP Digital Leadership Training and Development group
- Scottish Government Digital Health Equality Impact Assessment group
- National Scottish Restraint and Reduction Network
- National Care Service key stakeholder group
- SG roundtable - neurodiversity Bill
- SLDO roundtable re mortality research
- Session with CHAS and Kindred with Jason Leitch and families of CYP with complex needs
- Scottish Government – Doing things differently – our approach to the delivery of disability assistance
- UNCRPD (United Nations Convention on the Rights of Persons with Disabilities)– round table
- UNCRC (United Nations Convention on Rights of a Child) – supported presentation development of voice of children and young people with PMLD to be shared with SG committee
- Scottish Government learning disability virtual hub
- Scottish Government intellectual disability virtual hub
- COVID 19 UK research group

Correspondence

"When can I hug my son?", Miller, J	8th Sept 2020	This paper was sent to Clare Haughey MSP, Minister for Mental Health, Jeremy Balfour, MSP, who is the Convener of the cross-party group for Physical Disability and to Jackie Baillie, MSP, and Joan McAlpine, MSP, who both sit on the cross-party group for Learning Disabilities.
Response from NR (Learning Disability Policy Manager at Scot Gov) to "When can I hug my son?"	28th Sep 2020	
Email to Monica Lennon and Jackie Baille	29th Sep 2020	Email relates to support for family care givers and attaches - "When can I hug my son?" and response from NR (Learning Disability Policy Manager at Scot Gov).
Email to TCPU@gov.scot	24th May 2022	Provides information and insight into the group so that informed decisions can be made when considering action that will reduce childhood poverty Attaches: • Information about the people PAMIS support which includes links to short videos for further clarity • Recent International Woman's Day - Evidence for Equalities • PAMIS statement re Self-Directed Support • Reality of the caring role and chronic sorrow, which allows the reader to gain a sense of family life for this group and consider their reality of everyday life alongside the financial struggles families also face
Email to Scottish Carers Assistance	24th May 2022	Provides documents to enable a better understanding of the group of people PAMIS support Attaches • PAMIS statement re Self-Directed Support • Reality of the caring role and chronic sorrow • Recent International Woman's Day - Evidence for Equalities • Information on Poverty team

Email from NR Follow up on engagement meeting on Covid Highest Risk - meeting 6 May 2022	6th May 2022	Attaches • Notes from the discussion; • A copy of the comments from the chat function; • A Q&A including all the questions asked, and answers in full, including some PAMIs were not able to answer on the day. • Copies of the final CMO letter to those on the Highest Risk List

h. A brief summary of the views of the person, organisation or body, or the group(s)/individuals they represent, as to the lessons, if any, that can be learned from the Scottish Government's response to the COVID-19 pandemic.

142. The Scottish Government needs to better understand all groups within society. This must include robust information about people with profound and multiple learning disabilities. Having robust information will enable relevant government ministers to make better informed decisions in the future, about matters around social care and health provision. Not having all of the relevant information about a population does not tackle inequality but instead promotes inequality. Those involved in assessing and ensuring that all are considered must have all relevant information recorded to better prepare, should another pandemic or similar situation arise.

143. If there is no fundamental understanding of the person with PMLD, then it is not possible to appreciate the impact on their mental, cognitive, physical, social, medical and emotional wellbeing, of the arbitrary and unilateral withdrawal of the services that they depend on. There needs also to be an understanding that while people with PMLD may be vulnerable they are also valuable and have lives that are worth living.

144. In order to maintain family carer resilience in any future crisis, a greater awareness of the complexities, intense family carer role, and the necessary knowledge, understanding and high skill level required, to provide appropriate and safe support for this group, should be prioritised. Due to the complexities people in this group present, in order to deliver the meaningful and appropriate support necessary, decisions must also regard the required need for well-funded levels of support.

145. It is in everyone's best interests to access relevant PAMIS training. PMLD awareness training is recommended along with other training courses that PAMIS delivers. Everybody should have a good awareness of what is involved in providing guidance, advice, and care for the person with PMLD.

146. Training on PMLD should be mandatory for anyone caring for an individual with PMLD. If Scotland is to prepare for any future pandemic, a wider skilled workforce must be developed. Scotland's social care and health landscape has changed drastically.

147. Meaningful action must be taken to ensure all people, regardless of ability or disability are recognised and appropriate emergency plans drawn up.

148. The immense value and high level of unpaid care that family carers provide daily for a person with PMLD must be recognised and valued in the future.

149. Fundamentally, the biggest lesson is about listening; listening to families who are the experts. As an organisation PAMIS learned so much from them about issues, solutions and how to get through it together. So, it's about that collective wisdom and seeking to understand, to listen and to actually hear what people with PMLD and their families are saying. While PAMIS were seemingly listened to, in the end, nobody heard us properly. By listening to understand you achieve more.

150. There is also such a need for collaborative risk assessment to support our most vulnerable communities.

i. Finally, please indicate the number and types of relevant documents held by the group(s)/individuals that the person, organisation or body represents.

Document	Date	Explanation
Invisible no More", Fraser of Allander Institute (FAI) at the University of Strathclyde	October 2021	Demonstrates evidence on which to base effective policy decisions for people living with a learning disability is severely lacking
Hospital Pathways Letter	17th Nov 2020	Sent by Scottish Government in relation to social care being provided in hospitals

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed:

Personal Data

Dated:
03/04/2025