Scottish COVID-19 Inquiry

Statement of: Patricia Mary GRAHAM

INTRODUCTION

1. My name is Pat Graham, and my date of birth is Personal Data My details are known to The Inquiry. I am a retired Senior Tax Inspector and work voluntarily as the Chair of an organisation called PAMIS (Promoting a More Inclusive Society) which supports people with profound and multiple learning disabilities (PMLD) (as more fully described in the document totalling 3 pages and made available to the Inquiry named "PMLD Definition"), their families and carers. I am also a family carer for my I&S I&S daughter who has a profound and multiple learning disability. I&S has lived in a housing support service I&S

2. I have met today (Thursday 28th September 2023) with witness statement takers from the Scottish COVID-19 Inquiry team and am happy to provide a statement about my experiences of the pandemic as it affected my role as Chair of PAMIS.

3. I have signed the consent form provided. I consent to my information being contained within reports and published. I would provide evidence at any hearing if required.

4. I wish to give a statement to The Inquiry regarding my experiences as The Chair of the charity Promoting a More Inclusive Society (PAMIS), describing my role and the impacts the pandemic had on our services and how it affected our staff and families.

5. Please note that the use of the word "child" throughout this document refers to a person with PMLD of any age, from birth and throughout adulthood.

Organisational Overview & Responsibilities

6. I have been involved with PAMIS since it opened in 1994. As a family carer and a recipient of PAMIS services, I benefitted from advice, support and training from PAMIS when very little help was available from the local authority or the NHS to support me in providing the care that was necessary for my daughter.

7. In 2015, as I was about to retire, I accepted an invitation to be a member of the Board.

8. In 2017, the Chair announced their intention to stand down and I was invited to take over the role, which I agreed to.

9. My role as the Chair is more strategic than operational although I have always also been actively involved in providing support to staff and representing PAMIS at a range of steering groups, research projects, advisory panels, as well as the delivery of presentations and training to various groups, organisations and students. As Chair, I regularly engage with Jenny Miller (PAMIS CEO) to discuss strategy and practice and to identify risks and how to resolve them. It has always been the ethos of PAMIS to involve and engage with our families to identify how best we can provide the support that they need and also to put us in a position to share their views in all of the work that we do.

10. The Board has an upper limit of ten members, and we follow a membership format with half being carers and the other half who may not be carers but who have an interest in the organisation and in supporting and promoting our goals. We currently have eight Board members (soon to reduce to 4) as finding members with the appropriate skills is difficult. It can also be challenging to recruit family carers because time constraints resulting from

their caring role. However our current family carer Board members are very dedicated to supporting PAMIS and are actively involved in the decision-making process and representing PAMIS on many and varied platforms.

11. I would like to think that I am more than a figurehead for PAMIS. Given the length of time I have been involved with the charity and because we are a small charity, I have developed close relationships with many of our families and carers and enjoy close contacts with our team of Family Support Directors. I also have an excellent working relationship with Jenny, and we maintain regular contact to discuss current developments and issues and to plan for future activities and strategies.

Pandemic – Immediate Organisational Impacts

12. PAMIS is an outward facing charity, providing valuable face-to-face contact and interventions to help families and carers with their intense responsibilities caring for people with PMLD.

13. At the start of the pandemic, this stopped completely, as did all other medical and social care support services which our community are so very reliant on. This particularly impacted on the healthcare needs of our clients, many of which are complex and serious. The services withdrawn included:

    a. medical practitioners and allied health professionals
    b. direct contact with social workers
    c. the provision of day care services
    d. schools
    e. after school clubs
    f. respite and short breaks
    g. leisure and social activities
    h. support to families caring for a family member at home
    i. lack of access to family members living in residential settings

14. Care transitions also stopped, including moving from one school to another, leaving school altogether, moving from home into a residential setting, or transitioning from one care package to another, mostly from child to adult services. Families were left in limbo without access to any of the supports that are essential to maintain the wellbeing of people with PMLD, with no one to turn to for help other than PAMIS. This was very much their worst-case scenario with no light at the end of the tunnel. For many the fear, anxiety and practical implications of providing round the clock care were overwhelming.

15. What was particularly distressing for our families was the assumption on the part of those making decisions that they would be able to cope without all the services and supports that enable caring for a person with PMLD at home to be a viable proposition. While families had no alternative but to cope, the effect was extreme levels of stress and anxiety, physical debilitation both on the part of the carer and the cared for person and a significant reduction in quality of life.

16. As an organisation our immediate priorities were how to support our staff and how to support our communities for as long as the pandemic continued.

17. Putting our staff in a position to deliver our services to families was key as they are a lifeline to the people we support. Before Covid our Family Support Directors would also have been engaging with education, social work, and many other agencies on behalf of our families and that just ground to a halt.

18. Because most of our families were left high and dry, it was imperative to contact them all as quickly as we could.

19. We did very quickly get into a position to support all our families. A great deal of that was over the phone because a number of our families do not

have access to IT equipment. A lot of early work was about accessing and distributing appropriate IT to those families who were digitally excluded.

20. We also had to identify how we could adapt our services so we could deliver them online or provide that support to families who were digitally excluded. We very quickly put in place digital resources that families could access. These included family carer get togethers, counselling, art and music therapy, storytelling sessions, yoga, postural care and other training events. Later in the pandemic we were able to put in place outdoor events for families to meet up. Families were also encouraged to attend presentations, webinars, workshops, meetings and research groups at which we could share information and also give them opportunities to engage with other families and agencies. Many of these events still continue as they have been welcomed and appreciated by so many of our families.

21. In terms of our staff, their welfare was also very important, and we had to support them especially with the whole new dimension of delivering our service online.

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

23. The pandemic increased the workload for staff, who felt they were continually meeting brick walls. They could not really mix with their peers face to face because of working from home. This isolation and the pressures of trying to cope with the issues affecting families resulted in their mental wellbeing being adversely affected.

24. Not only were our families trying to find services, but staff felt an overwhelming sense of responsibility to do what they could to fill the gaps in services. This is why we decided that it would benefit staff to initiate daily team meetings to which all staff and indeed Board members were invited.

25. This was uncharted territory for everybody, but it was clear that the people we support were now even more vulnerable. It would be extremely challenging to provide meaningful and purposeful activity for them.

A great many of our family conversations were so very difficult. They could be very emotional both because of the difficult circumstances the families were experiencing and the challenges that our staff were met with in providing families with the meaningful services that they needed.

26. As local authorities and, especially, Social Work departments became increasingly difficult to contact, we really struggled to benefit our community in the way that we had prior to the pandemic.

27. It was impossible to get in touch with all the various services remotely and very challenging indeed to speak to a social worker even if a family already had a designated social worker.

28. I know our staff underrate enormously how much they really were a lifeline for our families but many of our families have since told us that they would not have survived without PAMIS. They knew that we were at the end of a phone or a zoom call even if we could not visit in person and that they could at least have a conversation with an empathetic listener who understood their situation.

29. It was all hands to the pumps really; discussing problems, sharing these across the team, lots of problem solving, coming up with solutions which Jenny would put into action. It was a very busy and stressful time for staff, all of whom were also dealing with their own personal Covid challenges.

Ongoing Pandemic Impacts

Internal and External Engagement/Partnership Working

30. In terms of my position as Chair of PAMIS, it was extraordinarily busy. My internal role included lots of oversight meetings with other Board members to consider how we could develop and adapt our services. I had very regular meetings with our CEO, Jenny, to discuss ongoing Covid impacts on PAMIS and our families, then recirculating all this information across PAMIS to ensure everyone was informed about our progress and also the challenges we faced.

31. I would have regular meetings with our Finance Committee, including preparing our accounts, and the other legal obligations for charities, regardless of whatever else is going on. We also had to consider the risks to the organisation if funding resources were reduced or withdrawn, as well as trying to obtain extra resources for the provision of additional online services to people with PMLD and their families and supporters.

32. Historically, PAMIS used to have to go cap in hand to ask to be included in meetings of importance to our community, but during and since the pandemic our profile and the regard in which we are held have been significantly enhanced; and as a result we are now invited to participate in high level meetings and research projects at which our voice is listened to and acted upon.

33. One of the unintended outcomes of lockdown, much of which is a consequence of how proactive Jenny has been in networking and the use of

persuasive debate, is that we are now invited to many more tables than we ever were previously.

34. The use of technology has made it so much easier and more efficient to attend meetings whereas before Covid many meetings could involve a great deal of travel. This improved our efficiency and reach significantly.

35. I was included in a wide range of meetings and engagements with a host of partners, whether with Scottish Government, MSP's, cross party groups and other non-governmental partners. I was able to explain how Covid was impacting on our communities to try to influence change in government Covid guidance.

36. I have regularly represented PAMIS on a number of national and international research groups, some of which preceded Covid. We were involved in trying to identify positive outcomes for PMLD groups across a range of issues, both related to Covid, but also to other health issues such as health checks, cancer screening and acute hospital pathways.

37. PAMIS is very fortunate to be considered a unique charity in that it is the only organisation in the UK and probably throughout the world whose sole purpose is to support PMLD families and much of the work we do is considered in the sector to be gold standard.

38. During the pandemic we still offered many placements to students from a variety of different disciplines including occupational therapy and GP students. I take the opportunity to have discussions with many of the students, not only as a member of the Board but also to provide a family carer perspective. I have also provided training on PMLD related issues to students from a variety of different disciplines at universities across Scotland.

Residential Care Settings

39. We work with people with PMLD in a multiplicity of different family settings but in the main people with PMLD are cared for in two types of setting. The first is where they are cared for at home by family members and the second is in a residential setting which could be supported accommodation, a housing support service and less frequently in a care home. What distinguishes supported accommodation from a care home is that in the former the individual will often have their own tenancy so it is their own home, which they might also share with usually only up to 3 others or it might even be a single tenancy. What was not made clear during the pandemic was how the rules and guidance might not be the same for people in these settings as they would be for people in care home settings. In future it will be very important for the distinctions between the nature of residential care for people with PMLD to be understood so that policy decisions take these differences into account.

40. People with PMLD in residential settings and their families were completely cut off and isolated from each other. All families could hope for was that their loved ones were well cared for by the professional carers but also that they were receiving the stimulation and exercise that they needed to maintain their physical, mental, emotional and cognitive wellbeing. 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. 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.

41. One of the greatest sources of distress to the family carer no longer able to see their family member was that they were likely to have spent a lifetime of caring for their loved one and 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 child's wellbeing.

42. My daughter's housing support service was, though, a standout example. As soon as the guidance changed to enable them to do so, they proposed that she should be able to visit the family home regularly as she always had in the past because the failure to do so was seriously impacting on her mental wellbeing.

43. Working with them we developed and used a robust risk assessment process to safely manage her home visits, meeting all Covid related safety measures.

44. However, this was not the experience of most other families with loved ones in residential settings, which is why PAMIS formed a team of family carers in similar circumstances which met very regularly to try to problem solve the isolation and exclusion most families were experiencing. I used my daughter's example to prove the point that visits could be achieved safely, sharing the risk assessment method with our team of family carers for them to share with their care providers. There were many benefits to our being able to see my daughter on a regular basis, including helping to lift her depression, being able to make observations about her behaviour and physical issues and being able to support her care team.

We also lobbied the Scottish Government to seek a change in the guidance so that families had greater access. Despite our families demonstrating this rationalised approach with providers of residential care, our efforts were broadly unsuccessful. Many homes were inflexible and adopted far more stringent rules far in excess of government guidance. Even when the rules were relaxing many organisations providing residential accommodation still refused to provide reasonable access to family members.

Coming Home Report/Dynamic Support Risk Register

45. The Dynamic Support Risk Register is a piece of work which comes from the Scottish Government's Coming Home Report.

46. This Coming Home Report is concerned with people, mostly adults but some children, with PMLD who are being supported in inappropriate accommodation, such as hospitals or older peoples' care homes or far from home, including outside Scotland.

47. The Coming Home Report recognises that for many people with learning disabilities, there is no suitable accommodation in Scotland for a multiplicity of reasons, including funding constraints, a lack of joined up services or breakdowns in communication. Some people with PMLD may be sent wherever a place can be found, whether it is appropriate or not.

48. A PAMIS family whose child was in a residential setting in England had to visit every weekend, staying in bed and breakfast accommodation. They provided additional care for their child because the professionals who cared for them did not understand his method of communication. This family is very involved in their child's care and have played a strong part in the Coming Home Report. This individual has now moved back to Scotland to appropriate accommodation near to their family, but this has been achieved primarily because of the efforts of their family rather than the other agencies involved in ensuring their health and wellbeing.

49. The Dynamic Support Register is a register which sits underneath the Coming Home Report. It has only very recently been set up and is to be used by all Health and Social Care Partnerships (HSCP) in Scotland.

50. It requires all specialists and professionals, families, welfare guardians and any others who are relevant to the care of a person with PMLD, to make sure the support that is provided to that person is dynamic. It is wholly about putting the person at the heart of the decision-making process to make sure that all housing and care packages are appropriate.

51. Because PAMIS is really very well respected, they approached Jenny asking who from PAMIS should be involved in this work. Jenny recommended me and another Board member in our capacity as Board members and also as family carers.

52. The Scottish Government team really listened and incorporated our views and comments into the Dynamic Support Register. We were particularly focussed on ensuring that there would be full accountability for this process, and this was very much essential if the Register was to function in the manner envisaged by the Scottish Government.

53. The register is now operational through every Scottish HSCP and NHS Board who will be accountable to the Scottish Government for ensuring that the Dynamic Support Registers fulfil their function.

Care at Home

54. Care to an individual with PMLD may also be provided at home, by the family and they may be supported by other services such as schools and after school clubs (for children), day services (for adults), respite, short breaks, personal assistants and other family members.

55. At the start of the initial lockdown, without warning they 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. Worst of all for many of the families whose family member has complex health needs and as a result depend on medical and allied health support, sometimes to keep someone alive, they were also unable to access any these services.

56. Added to this, 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.

57. This abandonment is still affecting families to this day because 4 years later services are not anywhere near back where they used to be. This is particularly the case in relation to day services and respite services. Families are legitimately questioning whether this might be a deliberate plan on the part of the Local Authorities to cut costs and Covid has given them an opportunity to do so.

58. We have a number of families who know that Jenny and I, on behalf of PAMIS are providing statements to the Covid Inquiry but they themselves are not keen to contribute, or those who have decided to withdraw because the prospect of providing their hard-hitting evidence, making them think about and revisit all the trauma they had to deal with is, for them, unbearable. Some may not be able to participate because, as carers, there are just not enough hours in the day. Others are unwilling to participate because they fear potential reprisals if they comment on the shortcomings of organisations who might be able to identify them. Jenny and I feel that it is our responsibility to speak on behalf of those who are unable to

participate for whatever reason to ensure that their families' voices are heard in the Inquiry.

59. As much as the process of talking about something can be cathartic, for many of our families it is still so real and raw, and they are still living with the realities and consequences of Covid.

60. Many families still do not see any light at the end of the tunnel. It's almost like PTSD, except it's not "Post" because it is still being lived now. Life pre-Covid was very challenging for our families and any problems were exacerbated significantly by Covid. Unfortunately while for most people Covid feels like a thing of the past for most PAMIS families it is still very much a current issue primarily because of the vulnerabilities of people with PMLD and the reductions in services.

61. An additional cause of anguish for families was that because of their additional caring responsibilities and the lockdown constraints, they were unable to continue to provide the same level of support to other family members such as aged parents.

Chronic Sorrow

62. Chronic sorrow is a recognised psychological condition which people may experience when somebody you love has PMLD and it is a feeling that does not go away. It is there all the time and affects the way you behave and the way you feel.

63. This is something which PAMIS focuses on, because it affects all our families.

64. It's a sadness you feel because your child has PMLD. As a parent you feel responsible for giving your child the best possible life but are often completely helpless to make that happen. Little can be done to assuage the

guilt. It is also about your grief for the child you might have had, the grief for your child for the life that they should have had and also the grief for the life that you might have had.

65. It does not matter how old your child is. This feeling remains with you for life.

66. Somebody once said that a mother is only ever as happy as her unhappiest child. If your child has PMLD, there is a limit to how happy you can ever be because that worry never goes away. Every waking moment you are either actively thinking about your child, or it is an ever-present backdrop to whatever else you are doing in your life.

67. Family networks are so fragile because you never know if something terrible is going to happen.

68. So when Covid came along it had a devastating impact. It got worse and worse and worse as lockdown impacted, withdrawn services were not reinstated and families were abandoned.

69. The whole Covid experience was truly awful for our PMLD families. A great number of parents had suicidal thoughts but would not be able to go through with it because of the worry about what would happen to the child they left behind or even worse, that they would have to take that child with them.

70. You worry what will happen if you die first. You cannot countenance the thought of what it will be like for the child when you die. You might think "if they die before me, then they won't have to survive without me". You also start to think and worry about the ongoing care responsibilities which will fall to the siblings. It is contrary to any parent's raison d'etre. No parent would want their child to die first and so you feel guilty about that too.

71. The siblings of people with PMLD often find that they are unable to live a fully independent life, to pursue their careers or live where they want. Many siblings realise that they will have to take on caring responsibilities when their parents die.

72. This is a completely unnatural way of parenting and is a completely unnatural expectation for siblings, too.

73. The Covid experience was dreadful for many siblings who live away from the family home as they were even more isolated from their brother or sister with PMLD because of geographical distances and the repeated lockdowns.

74. This all was a reality for many families before Covid but imagine what it was like as families struggled to deal with the enormous, ongoing impacts of withdrawn services and support. It was truly devastating.

Health Impacts

75. The health impacts on our group of people, arising from Covid, are dreadful. For most people with PMLD there will be no recovery to the quality of life, engagement or mobility that they had before Covid. https://warwick.ac.uk/fac/soc/cidd/covid19-learningdisability/results/

76. 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.

77. The impacts are already profound and will require more intense medical and social care interventions as the years go on.

78. One PAMIS family were utterly traumatised because of their Covid experiences. The complete removal of all health care monitoring and allied health services all compounded to cause devastating postural deterioration in their child, displacing all internal organs to such a severe extent that they died.

79. 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 wholly 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.

80. This is not an isolated case. This is a reality for very many of our families. Much pre-COVID research had already demonstrated that the rates of preventable and premature deaths for people with PMLD were significantly higher than for the rest of the population. This should have been recognised and acted upon by policy makers to ensure that reasonable adjustments were made for this group. However it is also noted that evidence on which to base effective policy decisions for people living with a learning disability is severely lacking ("Invisible no More", Fraser of Allander Institute (FAI) at the University of Strathclyde dated October 2021).

81. The ripple effect for families and communities is brutal. The feelings of complete abandonment and desperation is not caused just by personal immediate family experience. It is informed and compounded when families

share these experiences with other families in our PAMIS community; families who are close to each other because they are caring for someone with PMLD.

Strategic Planning & Key Themes

Internal Planning Structures

82. We have become, organisationally, much more risk aware. This is so important because we are a lifeline organisation for a whole community which has been and remains neglected and isolated from many services. If we did not exist, it would be a huge loss to our families.

83. Our direction and strategic outcomes are now very defined by the impacts of Covid.

84. It especially involves our staff because they are seeing, daily, how families are still impacted on, and all that knowledge is used to finesse our services.

85. Also, as lockdown went on, we were in regular discussion with parents and other support organisations. The parents and some of the care providers were very proactive.

86. A fundamental fact about our communities is that they have to deal with such a range of issues thrown up by caring for someone with PMLD, so they become excellent problem solvers.

87. All this knowledge and shared experience is drawn upon to develop what it is we do to provide really meaningful activity for our group of people, to support families and care homes.

88. It is very disappointing that organisations which provide support services of whatever description are often unwilling to utilise that expertise and knowledge when deciding what and how services should be delivered.

External Planning Structures

89. We have an international reach and we really are seen as being in the vanguard of developing interventions for the whole PMLD community.

90. Quite simply there is nobody else doing the work that we do. We share the experiences, findings and interventions we provide so that other families and communities can benefit.

91. It is ironic, though that we sometimes lose our funding because local authorities tell us without foundation or evidence that other services can now do what we do.

Funding

92. We are very robust on financial management. The loss or withdrawal of funding is a reality for all charity and third sector services. Even without the impact of Covid, it is an ongoing challenge and still has such an impact on our services and on our families. Our organisation's funding is always challenging and problematic. Our Scottish Government funding is often not approved and paid until well into our financial year. However, we are now a more financially astute organisation and ensure that we have sufficient financial reserves to enable us to continue to provide services in a crisis situation, as happened during the pandemic.

93. Our primary funder is Scottish Government and equates to about one quarter of our annual funding.

94. Local Authorities directly fund the Family Support Directors we have operating in their areas.

95. Beyond this we receive funding wherever we undertake specific projects, whether in local authority areas, through other third sector funders, or other organisations we work with across Scotland.

96. One of our key aspirations is to provide Family Support Director services across Scotland and for that funding to come direct from the Scottish Government, so that we would no longer have to apply through local authorities.

97. Without direct Scottish Government funding it is impossible for us to provide family support services to children, young people and adults with PMLD in all local authority areas because to do so we would have to submit sixty-four applications, ie two applications per local authority area. We simply do not have the staff to submit that number of applications, many of which are renewable after relatively short periods of time.

98. Children and Young People Services are separate from Adult Services. We would have to apply to separate funding streams to achieve a single holistic outcome for our PMLD groups, families and care homes.

99. This administrative and application process would be impossible for us as we only have a staff of twenty.

100. We receive some funding through legacies and gifts and we also do some fundraising but because we are a small organisation we cannot achieve the same level of fundraising activity as larger charities. During Covid fundraising was virtually impossible because of all the restrictions.

Treatment of Carers

101. We are very aware of the profound value of paid carers. One of the things that is important to PAMIS is the treatment of professional carers.

102. They need to be professionalised. This does not mean that they are not professional now; it means that as a profession they should be rewarded and recognised for the very important work that they do. They have huge amounts of experience, expertise, knowledge and training. This is so often undermined by the perception that they are unskilled workers who receive low rates of pay. The level of skill should be recognised and aligned with the NHS.

103. Care staff were left abandoned and invisible too. They had to deal with the full range of care needs themselves. Not only did they lose the support of all the allied health professionals, but also that provided by the families who would previously have supplemented and contributed to the overall care and wellbeing of their family member.

104. I know many were very concerned about the risks of introducing Covid into their clients' homes. The result was that carers really had to think about their own lives, with their families and friends but were always thinking about how they could prevent that risk of cross contamination to a very vulnerable community. Yet for that significant responsibility they were paid only around £10 per hour, an amount that does not reflect the responsibilities associated with caring for a person with PMLD. Many PAMIS families highlighted to us that they believed that care staff should be more highly valued and that their salaries should reflect that value. There is currently a crisis in the sector in the recruitment and retention of care staff which would at least be partially resolved by professionalising the sector and remunerating staff appropriately.

Acute Hospital Pathways

105. Although our charity work on Acute Hospital Pathways precedes the Covid pandemic, this remains a key outcome for us.

106. Whether people with PMLD are admitted with Covid related illness or not, they face extreme discrimination when admitted to hospital. It is a common policy for HSCPs to **not** allow the care staff that they fund to support people with PMLD when they are in an acute hospital setting. They pass over their duty of care to NHS staff who are ill-equipped to appropriately care for a group of people who have complex health and care needs and who almost invariably are unable to communicate those needs verbally or otherwise. This has an extremely negative impact on their healthcare.

107. When people with PMLD are unable to verbally communicate their needs, pain or fears then they will try to communicate by their behaviour which is often construed as "challenging". It is essential to understand that this so-called "challenging behaviour" is a cry for help that is likely to be the outward manifestation of an underlying physical or emotional problem for the person with PMLD that they cannot articulate. Despite their best efforts, NHS staff will not understand how to interpret this behaviour without the active participation of a known carer, whether paid or unpaid.

108. It exposes NHS staff to significant disadvantage, too, affecting their professional ability and obligations.

109. PAMIS has been campaigning for a change in this policy and practice for more than 5 years in one particular local authority and NHS area, with the backing and support of the Scottish Government, who are keen for this change to take place across Scotland.

110. It has always been incredibly challenging and much of our work and engagement with NHS and HSCPs has been to no avail, often in the face of bureaucratic cultures resistant to change.

111. This does not just affect people with PMLD. It affects any person with communication difficulties, whether it is a learning or disability issue, dementia, or indeed anybody else with a care package.

112. This may impact on many thousands of people across Scotland. They are deprived of the care and attention they need, because they cannot tell people what is wrong with them.

113. If care support is withdrawn, restricted or excluded from the hospital environment, all these people are disadvantaged. They are prevented from receiving the treatment they need.

114. HSCPs see their legal and ethical responsibility transferring to NHS as soon as they go inside any hospital. This is an abdication of their ongoing duty of care towards vulnerable people, prioritising administrative processes and convenience over the person-centred support people with PMLD are legally (and morally) entitled to receive.

It is vitally important to recognise that people with PMLD should be treated with the humanity and respect that is enshrined in various pieces of legislation, including the Equality Act 2010 which provides that reasonable adjustment should be made for them. This should include the provision and support of known carers 24 hours a day in any hospital or ambulance setting. It seems clear that the failure to do so will impact on mortality rates for people with learning disabilities which research already shows is many times that of the non learning-disabled sector.

115. **Organisational Outcomes and Silos**

116. We used Zoom, Teams and similar platforms to get to more tables, including at the top tier of Government, with strategic heads of services and national or international research groups.

117. I have a privileged position in that I am able to represent PAMIS as the Chair, but I am also able to talk about my own personal experiences, to personalise what PAMIS is and does.

118. When I share my personal experiences, it is difficult for anyone to contradict those views as they reflect not only my personal experiences but also those of other PAMIS families.

119. The overall feedback to my contributions and presentations, and those of other family carers and Board members, is positive and many attendees have really been moved. I have delivered PowerPoint presentations on many occasions to a wide variety of audiences both on behalf of PAMIS and on my own account. These will always include photographs and films and often music and poetry. They are always well received, and I am told that they enhance people's understanding of PMLD, PAMIS and also family life.

120. At a more local level, across public health, social and care services, there still remains a complete lack engagement and accountability. Even though we have frequently complained to individual HSCP and NHS Boards over the lack of services, they often just ignore us and are ignoring their legislative obligations.

121. There is scope to make formal complaints, but my own and other families' experiences have been disappointing in the extreme. The responses to such complaints are typified by lack of empathy, flexibility and understanding. It is extremely difficult to bring about reasonable change or improvement or to be adequately consulted. When organisations such as the NHS and HSCPs seek to make significant changes to processes and procedures then

under the Equality Act 2010 they are required to instigate an Equality Impact Assessment which would ensure appropriate consultation. It is very disappointing that they very rarely ever do so, and this renders many of the changes that takes place lacking accountability.

122. The lack of accountability existed not just at local authority level, but at a local level, with organisations such as care providers interpreting the guidance in their own way.

It was so unfair because we have families who have been isolated and excluded from the basic right of enjoying a family life. They already felt excluded, marginalised and invisible.

123. It is so important to be able to engage with Social Work because they hold the purse strings for our families and their access to services. Families' lives are controlled by Social Work, which pays for their care packages, schooling, day services, respite care, residential accommodation. If you are unable to contact your Social Worker, life is incredibly difficult. If you don't have a Social Worker, then you have to rely on the support of an overworked duty social worker.

124. When PAMIS was unable to contact the key personnel at a local level, we were left with no alternative but to approach whichever organisations that we thought might be able to support our case, whether it was the Scottish Government and cross-party groups, MSPs and MPs, Local Councillors or research groups and many others. It was all in attempt to try and get to the heart of the service delivery network.

125. The fundamental things which really affect families of adults with PMLD are transitions from children's to adults' services, day services, respite care and short breaks and access to medical and allied health professional services.

Lesson Learned

126. I am talking with the Covid Inquiry because I do not want any PMLD family to have to experience the fear, the anxiety, the trauma, the isolation or the devastating long-term effects of Covid should there every be another pandemic.

127. There needs to be significantly heightened awareness on the part of policy makers on the effects of their lack of understanding of the impact of their rules and guidelines on this group of one of the most vulnerable groups of people in society.

128. The impacts on the physical, mental, cognitive and emotional wellbeing of people with PMLD, their families, carers and the wider community will be felt for years.

129. Although the effects of Covid the disease on people with PMLD may have been difficult to avoid, the impact of the way that Covid was managed could and should have been dealt with more thoughtfully, with greater empathy and with more meaningful consultation.

130. Families are now less able to cope as a result of the debilitating effects, both physical and mental, on themselves and their family member with PMLD and as a result many more are seeking residential care.

131. 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.

132. Many people with PMLD will never recover to the level of movement, engagement, ability or quality of life they experienced pre-Covid.

133. For many the impacts hastened the deterioration in their health and for some resulted in early deaths.

134. Avoidable death and unnecessary suffering were caused when services were withdrawn. For some, their death was caused directly by Covid but for others their death was a result of the way that the Covid pandemic was handled.

135. Families are still living with the aftermath of Covid. For them it has not gone away. This is why, for example, when a hospital visit for a loved one with PMLD is required and you see no masks worn in the hospital environment, you do wonder if lessons have been learned at all.

Hopes for The Inquiry

136. That the inquiry recognises the importance of the front-line services that PAMIS provided to families, not just at times of crisis but every day and that in the early days of the pandemic, for many PMLD families this was the only service that they had access to.

137. That people with PMLD do have a right to a full life, not just a right to life.

138. That this right is absolute and enshrined in legislation and should be delivered by listening to families and carers and organisations like PAMIS who speak for people with PMLD.

139. That the inquiry makes it clear that families and carers really have to be at the heart of the decision-making processes surrounding the delivery of services, most especially at times of crises. They can advocate on behalf of vulnerable and often excluded people who cannot speak for themselves. They can explain the negative, life changing and potentially life-threatening impacts which will occur when all the services that they rely upon are withdrawn summarily and arbitrarily without consideration of the immediate and long-term impacts.

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:

I&S

Dated:

02|04|25