Scottish Covid-19 Inquiry

Statement of Jenny Miller, HSC0017

Introduction

1. My name is Jennifer Miller, Personal Data and my date of birth is Personal Data My details are known to the Inquiry.

2. I have met today (Wednesday 27th September 2023) with witness statement takers from the Scottish COVID- 19 Inquiry team. I am happy to provide a statement about my experiences during the Pandemic. I am willing to have my information contained within reports and for my statement to be published. I have completed the consent form provided. I would be willing to provide oral evidence to the Inquiry hearing.

3. I am the chief executive officer of Promoting a More Inclusive Society (PAMIS) and have been in this role since 2015. In all I have worked with or for PAMIS almost since it was formed, as a practitioner working alongside them and as a member of the PAMIS Board of Governors.

4. I am a HCPC registered occupational therapist, holding a Diploma of The College of Occupational Therapy. I am not currently practising in a clinical role but remain registered because I support occupational therapy, and other healthcare, students as part of their studies, especially when on practice placement with PAMIS and utilise my professional skills in my leadership role within PAMIS.

Organisational Overview /Pre-Pandemic

5. The purpose and operational business of PAMIS is outlined in the document made available to the Inquiry and totalling 9 pages (PAMIS-Promoting a More Inclusive Society-Background Information for the Scottish Covid-19 Inquiry) which I prepared in collaboration with Pat Graham, the Chair of the PAMIS Board. We have 20 staff, not all full time and 45 volunteers. We provide a range of projects and a family support service supporting families in five Local Authority areas. We have projects operating in Clackmannanshire and Dumfries and Galloway but also provide support via national programmes across the whole of Scotland.

6. Combatting health inequalities and tackling the shocking mortality of people with Profound Learning and Multiple Disabilities (PMLD) is a core strategic goal (link to information about this stark inequality https://www.sldo.ac.uk/our-research/determinants-of-health-and-inequalities-research/life-expectancy-and-mortality/causes-and-rates-of-death-in-adults-with-learning-disabilities) and within this we have led on the development of the PAMIS 24-hour postural care education and

support and have been instrumental in the development of a Scottish Postural Care strategy - Your Posture Matters (https://learn.nes.nhs.scot/60813#).The consequences of postural deterioration can be fatal, and families are subject to a post code lottery of whether they can get access to treatment and equipment (information about postural care https://pamis.org.uk/services/postural-care.

7. We work with children, young people and adults with PMLD although I recognise, I keep talking about a family carer's child but in the context of the whole age range. The reality is that many families with a child/adult who has a PMLD will be involved to a very great extent in providing and supporting their relative's very complex care needs from the moment they are born and throughout their lives, whether that child remains at home as they get older, moves into any form of supported accommodation or into a private tenancy, with wrap around care support.

8. One side of PAMIS is the family support and the other is developing practice to support people with PMLD to contribute and be valued within their communities. This practice development also supports our learning and development programmes, supporting others to deliver best practice to people with PMLD and their families. We have been involved in a number of research developments, for example our multisensory storytelling, which started as a research project but as it matured, we rolled it out, training families and other people to use it with people with PMLD.

9. We have a global reach and some of our work is world renowned. One real success was the research and subsequent practice in bereavement and loss as it is felt and experienced by people with PMLD. Historically, it was considered that they wouldn't feel loss, they wouldn't know. But as our families have been telling us, they do. Research now proves that experiencing emotions develops very early in the brain's development and therefore means that all people with PMLD no matter how their brain has developed will experience loss, isolation and emotions. This was a really important bit of research to understand and address how to offer support to our group of people with PMLD in these circumstances.

10. Our Family Support Directors work with families of people with PMLD, especially at times of crisis. We don't advocate, we empower them to represent themselves and their relative with PMLD, so that they can have what are often difficult conversations with social work or other health and social care practitioners regarding care packages or interventions. This is particularly important when young people with PMLD are transitioning into adult services. Families will regularly ask for us to be a second person in the room where these conversations are happening.

11. The reality is a great many families have to stop working when their relative leaves children's services and moves into adult care. Lots of the support and coordination is lost and families have to assume those various care and indeed coordination responsibilities themselves.

12. This can be a very stressful role for a family support director. Finding positive ways to support families lightens this load for example organising and running family fun days, inclusive leisure sessions and friendship clubs. Families tell us that they feel confident coming to a PAMIS event because they know that we promote inclusivity, all the activities provided are accessible, appropriate and meaningful, and that they are all risk assessed and safe for this group of people. The communication of someone with PMLD can be quite different, can be seen as challenging by those who don't consider it to be a communicative response, but families all recognise this and therefore feel comfortable, and that inclusivity makes them feel safe.

13. We also work with families who are bereaved, again linking back to the world leading research project. But even after the loss of their relative with PMLD our involvement doesn't stop. Many of these parents become volunteers and we have a few of them working for us because their experience is so valuable and their commitment to supporting other families is a key driver.

14. We utilise improvement methodology in everything we do. We work closely with families who share their knowledge, vast experience and insights and develop research and then interventions that will benefit the wider community of people with PMLD and their families across Scotland and indeed wider internationally. We enjoy a very clear and efficient exchange of information and learning throughout PAMIS and for us, our most valuable experts are our families. Our practice development and learning and development work reaches out across the whole of Scotland.

15. In fact, it's so very true that if we get things right for the most complex group of people within our society, we will get it right for so many more.

16. However, very often many families are forced to give up work because of the reduction in care packages and also because of the severe nature and overwhelming responsibilities which parents have to contend with. These can split families and care then defaults to a single parent. All of this has a detrimental effect on the well-being of the entire family unit.

17. We are a very small team at PAMIS, and I have to take on a number of roles. Primarily my role is to lead the organisation supporting the development and implementation of our strategic goals. This entails engaging on a national strategic platform with Scottish government, across sector groups that support people with learning disabilities or those

supporting inclusion. I work with the PAMIS Board and the Finance, business and development director to assure the governance of the organisation and also manage and support our staff group. In addition, I provide hands on support for families and people with PMLD and support a range of undergraduate health and social care students on their practice placement. I meet regularly with the staff often on a daily basis. I think about 30% of my time is working directly with families and the remaining 70% is leading the organisation including preparing funding applications, supporting the development and implementation of our strategic plan alongside the PAMIS Board, and a range of other tasks as previously highlighted.

18. I'm often out and about with our "mobile changing places toilet" (https://pamis.org.uk/campaigns/pamiloo/), which we know as the PAMI-loo. This travels across Scotland and is used by our communities at a range of events, including those organised specifically by PAMIS like fun family days. There are only about 260 changing places toilets (https://pamis.org.uk/campaigns/changing-places-toilets/) where people with PMLD can have their personal care needs met with dignity and respect, across the whole of Scotland, so most people with PMLD and their families are restricted to where they can go out or have to change on a toilet floor, in the back of a car or remain at home.

19. Volunteering to support the Pamiloo keeps my feet totally on the ground because I am regularly engaging with families first hand. I also work closely with staff, at times helping them with complex cases that they have to deal with.

20. We have core funding from the Scottish Government Mental Health Directorate. We work with the Learning Disability team of civil servants with whom we have strong links. We also work with the Scottish Government's Disabled Children and Young People Group. Some of our funding comes via these groups. and their teams seem to understand what we do and via our work they have recognised the pressures affecting families, carers and people with PMLD.

Pandemic Impacts

Organisational Impacts

21. I just remember the phone call that we had to move out of our head office in Dundee on the day of lockdown, "that was it, get out."

22. Our organisation moved very quickly to adapt to the immediate pressures of COVID. Our staff have always been very flexible and adaptable taking on new responsibilities, adapting their role and also are used to having to work from various locations.

23. Very quickly we adapted to the use of virtual technology and had grasped the use of Zoom. Within the first week we had had set up virtual full team meetings, supporting each other and clarifying how we would continue to support the families.

24. Within a couple of weeks using Zoom, and other electronic/virtual means, but mostly by phone, we had contacted all of our clients on database to update them very quickly about how our services had changed to online from face to face.

25. Our often 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.

26. Because we are so small and reacted really quickly to lockdown, we were instantly able to feed what our 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 NR was so incredibly sensitive and supportive.

27. One of the biggest issues we identified really early on was that highly skilled allied health professionals, were being redeployed to wholly inappropriate roles, which had no use for their skills, such as being welcome teams for people arriving at hospitals. Our families, carers or people with PMLD may not die of Covid, but the support these professionals afford was invaluable. Taking it, all away would and did very quickly have a profound negative impact on their overall health and wellbeing. What on earth was that all about? A wholly inappropriate use of their skills.

28. I do wonder why those professional people didn't stand up and shout out about that, to remain involved and committed to their group? There was a long and sustained period of time where there was absolutely no health or social care input with families.

Supporting Staff

29. Our staff support was instant; concerned that staff were out there alone, working remotely from home facing some really emotionally charged situations, we quickly got to grips with daily digital meetings. It really developed some very close relationships across the team which we never really had before. It's been so successful we still do it. It really does make

us more of a team. But you would also get a sense that people were struggling so you could pick up the phone and check with staff individually.

30. As things went on, we found that the Family Support Directors were really struggling. It was at one Christmas time, but I can't remember which one, many of our families were having a horrific time, with some having real suicidal intentions. Knowing this, we used the online staff meetings to support our staff in their engagement with these families, whilst also making sure that the issues affecting families were managed to the best of our ability.

31. Also, staff were struggling with their own lives; lockdown and all the impacts had been going on for so long. This was a difficult period for all of us.

32. The practice development team were creating a whole range of resources and support and still leading on their individual roles. At times the family support role was so overwhelming for the family support directors they weren't always able to give the positive feedback to the other team and I think at that time it made the practice team feel undervalued. We did want to involve staff with all sides of our operations, but they were so very busy, they were just unable to devote time away from the families they were working with. This was a tricky time, but we got through it. I was lucky enough to have access to Inspiring Scotland staff – NR NR and NR and to the learning disability portfolio members. This group met regularly and for me this was a lifeline and also a safe place to explore solutions to issues. I also worked with the Kings Fund and GSK Leadership group and was able to get coaching for one tricky internal staffing issue.

33. Our staff remained dedicated and committed, we were able to continue to fund them all and we didn't lose any staff over this period or subsequently. Our volunteers remained in touch although for some roles there was little to do – e.g. the Pamiloo. Other roles like the online arts and crafts were reliant on this volunteer workforce.

34. We did use furlough for one member of staff who was not able to deliver on her project because of COVID. She was working with CALMAC, basically looking at ports to review their provision of changing places toilets. We spent some time assessing if we could legally furlough because if not, this could have been a major impact for us, because it was a big consultancy contract.

35. CALMAC were really supportive and allowed us to resume the work later on when we were able. This supportive and compassionate approach was

amazing for us. Although not huge to other organisations for us this was a big contract and one, we were keen to complete.

Using Digital Technology

36. I.T. was a particular problem; at that time our IT was still provided/ facilitated by Dundee University infrastructure. We were in the process of moving to a new provider but at that time were reliant on Dundee University support. We had a finance programme on a server which stopped working and left us having to manage our finances manually/paper based. Our database of families was not on the cloud and so these also had to be inputted manually. However, we quickly got to grips with the realities and data protection issues surrounding our organisational use of IT and it really started to reap some benefits for us, our families and our wider network of partners.
37. We were also supported to access "Near Me" for our counselling appointments thanks to our civil servants and NR. This provided a secure platform for sessions.

38. We hosted webinars which had a UK wide and international reach. We developed a digital postural care learning resource, an area that we have been leading on for the past 15 years. Basically, for our 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.

39. Suddenly, this was an issue for "Joe Public," everybody realised they needed good posture to deal with the effects of Covid. Our staff member, NR who led on our 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. We also turned our postural care training into an online programme for carers and families. We had a small group of family carers who were postural care trainers and who contributed to the course. This was a really positive activity for them.

40. We had been working on a postural care strategy for Scotland alongside the Scottish Government AHP lead for children and young people. This has been a priority for our community but getting others to engage across the wider health teams has been problematic. The demand for this resource because it supported effective management of COVID meant that the interest in the development and launch of the strategy was probably pushed forward several years.

41. One of our most successful 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.

42. When the world started to open up and care resumed, families ended up with a range of new carers who could look at this digital passport and understand much more effectively and very easily the person's care needs, what they like and don't like; all vital information for engaging with someone who cannot explain nor narrate these things themselves.

43. This was shared as far and wide as we could. We decided morally that although prior to COVID this was a possible income resource during COVID we would share it for free and support others to use it. In the future we would like to see it rolled out in every nursery in Scotland, a tool to document important aspects of a child's life and development. It has a practical element, too, we never know when we will need this information, when people may unexpectedly be hospitalised or have profound life changing injuries.

44. The joy for us was that our digital solutions and resources were reaching across the country supporting paid carers in supported accommodation, residential settings, care homes where they were desperate for any and all support to help them deal with the effects of lockdown (Our online resources - https://pamis.org.uk/services/virtual-activity-programme/)

45. There were challenges for families who could not get the paid carers or supported accommodation to use zoom or access the resources on the web. Some just didn't support it, for whatever reason. Yet we had so many, paid carers who moved heaven and earth to get people online so they could participate and engage with families and with the array of online activities which we developed.

Digital Exclusion

46. There are a number of families who are very untrusting of emails and telephone calls, because they have had so many negative experiences with local authorities. They will only really answer the phone if they know who's calling and tend never to engage digitally with statutory services.

47. For those who are digitally excluded this caused some real problems, so it was all about making sure we had the right contact numbers for families.

48. Also, a number of single parent families are on or below the poverty line. Some have other children who need those devices as well, so altogether, the financial realties are, for them, prohibitive when it comes to accessing IT.

49. However, our own digital health lead acted really 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. The big difference was being able to pay for the internet costs.

50. For us, digital was really helpful because as well as mobilising our core family support, we instantly started developing online resources. One example was a parent, who couldn't see his child in his residential care home, so he would download the activities and post them through the home's letterbox, so his child had the activities to do with his carers. The parent felt he was not only helping his child but also supporting his child's carers.

51. Initially we were really concerned was about how someone with PMLD would use IT. We worked with a number of practitioners and other experts to identify how we could actually engage and work with that community.

52. We were really surprised how well people did then engage, especially those with visual impairment, who really reacted positively to music activities and hearing friends' voices online.

53. The music practitioner was equally amazed at how successful their interventions were online; I think it was because participants were more focused because there were less distractions. We even hoped to get a Christmas Number One hit, using the voices from a multisensory story project that had been recorded but that didn't come to fruition, unfortunately.

54. This whole IT development really brought families together actually. The most popular event, which still goes on, is the PAMIS Friday night virtual disco.

55. We had so many skilled people, including our Occupational therapy students on placement with us that we developed a whole range of online resources, to be used by parents and carers, wherever they may be. We 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.

56. We still had families, though, who still couldn't get on, especially those who were caring for somebody with complex needs, but also needing to home-school other siblings and working remotely. I don't know how they did it, it must have been incredibly hard, and many highlighted that they were struggling to find the time to engage with it all.

PPE / Infection Control

57. One of the earliest questions from families was about where to get PPE. The Scottish Government were good at getting information out to us about this all, and if we were unsure, we could go to our own government links for advice and clarification.

58. Some local authority areas were more organised than others and they absolutely made sure that PPE was readily accessible. One of my abiding memories was a member of staff who had to source who should be providing the PPE locally, she then had to inform them/the local authority that they were supposed to be handing it out.

59. There were some issues regarding categorisation between paid and unpaid carers and also where the voluntary sector could go to access PPE. There was definitely confusion at the beginning depending on who you were. We are not a service provider, but we provide a service; because we were not perceived as front-line staff, we had some issues in accessing for example testing kits as we began to move out of the pandemic.

60. As the high-risk register was dispersed, moving out of the pandemic, accessing PPE, and testing became an issue. I wanted staff to be self-testing before engaging with our families. Though we are not hands on, we do have to get close to people so there is an inherent risk there.

61. The instruction was that the volunteers working with PAMIS could be tested, but not paid staff, which was ridiculous. 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. Although COVID was decreasing families still felt their relatives were vulnerable and we all agreed it would be beneficial to minimise the risks.

62. Basically, if you didn't tick all the boxes and despite us explaining our roles or rationalising why we should receive the testing kits to mitigate cross contamination risks, we didn't get them.

63. Also, despite national guidance on PPE, which was clear, by the time it filtered out to various authority areas it was interpreted differently. Some

would think laterally, 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.

Government Guidance

64. It was essential that people with PMLD were engaged in physical and multisensory activity. For them, being trapped indoors was incredibly difficult. We felt that through the civil servant team we were working with that these messages were heard by the government and that the guidance was changed to encompass this. However, the public were really unhelpful; people in wider communities would challenge them when they were out, especially when families 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.

65. Families became really nervous about confrontation whilst outside. Some of our group have profound disabilities but are mobile, not wheelchair users. Certain elements of the public did police what they saw as infringements, despite guidance for our group which permitted them to be outside; it was quite difficult for our families.

66. It was also difficult when the guidance kept changing. We didn't put the guidance on our 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 our family support directors to then share with families. It was tough to remember what was right or not and what had been said.

67. The Family Support Directors were really keen to see families, 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 we were keen to have restrictions governing this essential engagement reviewed as quickly as possible.

68. One family support director worked really closely with a parent whose child had PMLD, and their spouse, the main carer suddenly died of COVID. The family had been engaged with us but no other services, because they had been managing their child's care well enough by themselves. The family support director was the only person in touch with this parent and had to coordinate other services to engage. They were the person gowned in PPE visiting in such tragic and dire circumstances.

69. In this case we also worked with Scottish Government civil servants to explain and successfully justify that their extended family, who lived very far away, could travel and help support the remaining parent with the child's care.

70. We also worked with a number of families who really struggled. Working with them we undertook very stringent risk assessments so we could identify safe ways of engaging with them face to face.

Medical Care

Routine appointments – Physiotherapy, Occupational Therapy, etc.

71. There is a real complexity about this because a number of healthcare services and interventions were delivered at school, so when we were in lock down everything everywhere just stopped.

72. Because all the services stopped, with Allied Health Professionals dispersed elsewhere, day services closing, hydrotherapy services closing, the whole overview and delivery of our group's physical health, care and wellbeing halted.

73. These groups rely on people to support them 24/7, many require support to mobilise/move many require equipment, access to hydrotherapy for example. What families were telling us was that the skills that their relative had developed, skills which take this group far more time to develop, were being lost and families feared that they might not regain them. The withdrawal of health services meant that their physical health regressed and again families are concerned that this might impact their future wellbeing. A key concern with limited or no access to allied health care practitioners was the impact on the person with PMLD's posture. PAMIS are heavily involved in the promotion of postural care which prevents or minimises body distortion, and without which can lead to premature death. This is ordinarily monitored by physiotherapists, occupational therapists, paediatricians and the wider clinical community.

74. 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. We also heard from families about equipment being sent out with little or no instruction in use and in some cases inappropriate regarding size and ill fitting. We 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. We also recognised that without appropriate equipment to move the person with PMLD the relative/family carer was at risk of injury. 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. We ran online workshops with experienced consultants to address the issues and to provide support in safe handling and moving processes. Families were really grateful but some of the things they highlighted were really difficult and it was appalling that families were left in that situation.

75. But 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, well who knows where they are now in terms of their health. They just disappeared from routine medical interventions.

76. One family was supported to raise concerns about the complete lack of postural care and an inappropriate wheelchair which they felt has resulted in a significant deterioration in their child's posture with internal organs being wholly displaced. This has caused tremendous impacts on their overall health, extensive periods of hospitalisation and very restricted pulmonary health.

77. We know 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 and the loss of broader physical skills which will have taken years to develop.

78. There were also examples of ill-informed decisions being made by social care budget holders. We 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.

79. Despite the cost being equitable, a social care panel, who direct the care package 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.

80. One of our 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?

81. 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 impacts of COVID pandemic on this group's physical health is nowhere near being dealt with. The impacts are still being felt.

Emergency Medical Care

NHS Clinical Frailty Scale

82. A highly stressful period was the introduction of the Clinical Frailty Scale, which was intended to assist medics with decisions about who could or should, be treated.

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

84. This proposal about the scale sent absolute panic through our community One parent told us about how she had to race down the motorway to get to the hospital where her child had been taken because they thought they would make a judgment about the quality of their life and not offer treatment.

85. This rationale of judging another's quality of life is, according to a student that we had on placement, backed up in medical journals. However, this physio student concluded after a practice placement with PAMIS that if medics just concentrate on 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.

86. This scale was declined in Scotland after we 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.

Acute Hospital Pathways

87. 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. 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, be unaccompanied?

88. 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. We have been working on this pathway for a few years, led by a family carer.

89. But even though we had this agreed as policy, it did not always filter down. We were frequently called by families to say they were struggling to get access at the 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.

90. This is more pronounced when the child is, technically, still someone’s child, but is actually of adult age. Paediatric services are more understanding and aware of these complex needs, but not so much when the child becomes an adult and no longer in in paediatric services.

91. Health and Social care must work together so that there is a hospital pathway so that paid carers can go into hospital. One of the civil servants in the Learning disability team at the Scottish government worked with NR a family carer who had raised this issue, and PAMIS. This led to a 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. NR NR and I met with HSCP Chief Officers, and they admitted that until we had presented the narrative about the letter, they hadn’t understood why the letter had been sent; not understood the impacts and realities facing our group, all of whom have a range of complex needs, when going into hospital.

92. This issue precedes the pandemic and is still an ongoing battle. We know that 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 they will require hospitalisation, more frequently.

93. 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.

Mental Health

94. Before the pandemic we were a part of a group led by NR NR developing a research project looking at interventions for people with PMLD who have become depressed (Jahoda, A., Dagnan, D., Hastings, R., Gillooly, A., Miller, J., Baines, S., & Hatton, C. (2024). Adapting psychological interventions for people with severe and profound intellectual disabilities: A behavioural activation exemplar. Journal of Applied Research in Intellectual Disabilities 37(2), e13199).

95. When Covid struck, rather than curtailing this project, the researchers/practitioners adapted it for online and this was a really positive outcome for parents and carers because people weren't just left but were enabled where possible to engage through a screen to overcome their depression and for some the impacts of lockdown.

96. It includes a range of meaningful and purposeful activities to encourage those with PMLD who are depressed to engage with their parents or carers.

97. It was especially good for paid carers working in supported accommodation, who didn't understand how meaningful engagement was for our group. It gave them ideas and activities that they could use, including one where even though it looked as though the person, they were working with seemed disengaged, it provided a few tools which encouraged them to persevere with that engagement.

98. The unfortunate reality is that for many of our group the only level of engagement they get is when they are having their immediate personal care needs met, such as being fed or hygienic care.

99. It's not a criticism of care staff, they are not trained practitioners such as occupational therapists, clinical psychologists, learning disability nurses, and they simply don't know what they don't know. But lack of purposeful and meaningful activity and engagement can lead to depression.

100. That’s why this online activity was so important, especially when all other visits and outdoor sensory input was not allowed.

101. Also, the whole lack of routine when all activity ended, really had a profound mental health impact on people with PMLD. It was clear they were withdrawing, becoming depressed and lethargic. So many of our group suffered tremendously as a result of losing that sensory input and activity; not being able to get out into the fresh air really affected them both physically and mentally.

102. We also developed the Imagination Toolkit, using multi-sensory storytelling (https://pamis.org.uk/creative-arts/the-imagination-toolkit-a-multi-sensory-story-resource-for-challenging-times) to explain to our group what was happening as a result of all the Covid realities, like lockdown and no visits. We worked with family carers and an educational psychologist to develop this toolkit.

103. But what we found was that people were still dealing with the traumas that Covid had caused, we were worried that for many people, including paid carers that this might re-traumatise them.

104. As a result, we did not fully release this resource at the time but have subsequently provided training and support to staff teams to use it.

105. It will have value in the future because it will support exploration in a safe time.

106. For family carers the impact of the pandemic on their mental wellbeing was serious. They were invisible, there were wholesale negative impacts caused by the withdrawal of services and the increasingly insensitive approach adopted by care services.

107. The reality is that family and paid carers were, emotionally, on their knees, asking for help and not getting anything, not knowing where to turn.

Social Care Services

108. A lasting experience of Covid is that the intensive role required of parent carers, who were supported at home by a range of services before Covid, but which stopped, completely, overnight, meant that there were a number of parents who submitted requests for their children/relative to go into residential/supported care (“Learning disabilities and the value of unpaid care”, Fraser of Allander Institute (FAI) at the University of Strathclyde dated September 2021).

109. Before Covid, their imperative was to keep their relative at home. But parents are exhausted, many feel utterly abandoned by all their services, treated very unfairly by Social Work Departments, remaining almost invisible and left behind as services resume and the rest of the world gets on with living.

110. But there is such a short supply of appropriate accommodation, with properly trained staff, so some Social Work Departments are now trying to place people with PMLD into older people care homes, which is wholly inappropriate.

111. Our group are not old, many of them are very young. This location is not appropriate, and the concern is that staff in these homes will not be trained to work with this group and may not have the appropriate skills to provide meaningful activity and care.

112. The other reality is that there are simply not enough appropriate supported living resources and it's really hard to recruit social care staff because there aren't enough candidates and even less with the necessary skills.

113. I do really feel that we provide very little support, training and value to the workforce working with people with the most profound needs. It is so very unfair for them.

114. Another key issue was with day services and the lack of them; again, it was about the guidance. I remember the day when Nicola Sturgeon said that one of their key objectives was to get day services and respite services open for our most vulnerable groups. This was early on in the opening up of communities, but it didn't happen.

115. Though some small numbers of day services remained open throughout Covid, albeit operating a restricted operational model, it was clear that the majority of Local Authority areas closed and failed to reopen.

116. What was unclear was, why? Was it because authorities just thought it was all too risky to open them? Or because they were using them for alternative operations such as vaccination centres? Or because older people were now using these premises? Or was it because they thought that this was a great way to redesign their care services and never re-open them? It is something which we can't help but feel is part of the reason why day services have not really resumed.

117. Self-directed support is a fundamental part of accessing appropriate and more focused care, a great deal of which is Social Care. Despite explicit Government instruction that care packages would not be reviewed or

reduced during the pandemic period, we have examples of 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.

118. This was because the families were perceived as managing to deliver the care themselves.

119. The reality is that all care had stopped, as a direct result of covid, not at the behest of families. And that these families were and are on their knees dealing with what is often 24/7 care.

120. So, despite 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.

121. We fed this into our government network, and these were often very emotional meetings, but I feel that as with a great many other issues surrounding government guidance, local authorities ignored this altogether and some of the officials we worked with were struggling to have their and our voices heard in the wider government and with local authorities.

122. 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.

123. The impact was that the experiences and valuable input from our carers and families was ignored, which caused significant and avoidable negative impacts being unnecessarily imposed on our group.

Isolation and Family visits

124. People with PMLD will either remain at home with their parents, or parent, or stay in a range of supported accommodation/living arrangements. The residential care units are not older people's care homes but are specific to their needs, or they stay in supported group home accommodation, with care provided by a care provider. They might even have a private tenancy with Self Directed Support to fund appropriate, focused support for all their needs.

125. For a group of people who are unable to comprehend why their families are no longer visiting, this had a really depressive/negative impact. For

others, it meant that this lack of visiting caused the relative to forget who their families were, relationships broke down.

126. We have families which are getting older and because they have been excluded from their relative with PMLD, they have commented about the fact that they will never get those years back. What happens if the parents die whilst their relative is in care and they haven't been allowed to engage with them as they had before? It's so emotional and very sad.

127. The thing about visits by families to wherever their relative was living, is that families were not just visiting their adult child, they were intrinsically involved in their care, often intimate personal care that other people didn't carry out.

128. That is not a criticism of paid care staff; it's a reality that demonstrates how very involved families remain in actually providing care for their loved ones. Going into a residential care/supported living environment definitely does not mean that those care responsibilities are immediately devolved or abdicated to paid care staff. Most of our families remain very involved with the provision of care in the supported living environment.

129. Paid care staff within the persons home were also under a huge strain, suddenly providing all the care and activities without support from families and the wider team. This was an isolating and emotional time for them.

130. We have great paid carers, but they are not always aware of the importance of providing purposeful, meaningful activity to people with PMLD. The visiting families are a lifeline for their relative not living at home and for their paid carers too.

131. With this in mind, we asked that these family visitors were seen as members of staff, because they were providing a service.

132. Families themselves were reporting to us that they were seeing a huge deterioration in their relative.

133. We work with the real specialists in infection control: the families. They have been making risk assessments regarding their relative/child's safety and wellbeing from birth. So, we worked with them to identify what range of risks would be assessed and how. We developed a robust risk assessment process, addressing PPE, infection control and the whole range of issues arising from Covid. We used this risk assessment approach when reopening our activities, always sharing the assessment with families so they could add. We also suggested that this shared approach should be used to facilitate family visits including allowing people home on home visits. One family had a care provider who followed

this approach, and this enabled their relative to come home. The parent added far more risks and mitigations than the provider, but it was a shared approach and acknowledged the family's expertise.

134. We submitted a paper ("When can I hug my son?", Miller, J- September 2020) to 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. We straddle these two groups through our engagement processes.

135. Our paper explained the issues regarding the disparities across the country regarding visits into our groups' care and shared accommodation. We outlined the risk assessment process, and we 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.

136. We 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.

137. We 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.

138. I believe Jeremy Balfour asked questions about this in parliament so this should be on public record.

139. However, despite the support which we received and the very good support from civil servants who really understood the issues and concerns, the issue was not overcome.

140. What we found was that though the Scottish Government did put out 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.

141. Even when we had staff speaking with public health in the local HSCP or residential setting staff one day and agreeing to use the risk assessment, when phoning the next day to go through that process, the whole thing was refused, no permission was granted. I do believe there was just a

complete lack of understanding of how risk assessments worked, and their use was very subjective.

142. We made representation to the Care Inspectorate who were supportive of the issues and through them we engaged with the Scottish government team who set up the group to look at care home visiting. However, there was confusion about our group who lived in supported accommodation and the differing rules for them versus a care home.

143. We also shared our work with the Government's Social Care team, outlining the good practice we had identified between specific care providers and families, and the risk assessment process that facilitated improved outcomes when it was used. They were really keen that this should be adopted, but I think that they were powerless in getting the local authorities to act on guidance or advice. The guidance about risk assessments and the need to do these collaboratively was given by the government and we had examples of how this could work but it, and we were all ignored at a local level.

144. We were part of the Scottish Government "Open with Care" which then also incorporated Anne's Law, reference group. Our ask about access and consideration of family carers being seen as front-line staff was a similar ask to the Care Home relatives. 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 (Coronavirus (COVID-19) Supported Housing: clarity on guidance that applies to supported housing settings- July 2021).

145. In reality this meant that families were deprived unnecessarily in seeing their relative and, for some, up to 18 months of separation. The new Health and Social Care Standards for visiting and staying connected: Guidance for providers-March 2022 should also be incorporated into other places that people live where restrictions are imposed such as supported housing. We would want at the centre of any future recommendations for family carers supporting people in supported housing that they have the same access rights as is being suggested for those in care homes so this separation position is never allowed to happen again. We would like this to be an addition to Anne's law so that everyone is clear about the differences and needs of those in the service. It would be important in the future that there are clear definitions of the housing support models and what legislation impacts on them.

146. When we began to open up our own services, I was terrified that we might bring our groups into contact with Covid.

147. But I was reassured by our Family Support Directors because their feedback, directly from families, was that we should carry on, use and refine our risk assessment and share it with them.

148. Families all told us that they would always do their own risk assessment on top of any external risk assessment, cleaning the house, taking really sensible precautions but wholly committing to working with us and making our risk assessment a really informed process. This was in the early stages of lockdown, it really helped individuals who were at risk of deteriorating health and wellbeing, which was a greater risk than Covid. It really worked, but was just ignored by statutory services, which compounded the feelings of abandonment and isolation felt by our community, being left to sort things ourselves.

149. Also, when the world started to open up, paid carers were, rightly, taking the opportunity to go on holiday with their families then returning to work to care for our group.

150. But the parents didn't go anywhere; they remained at home keeping themselves almost excluded from the rest of the world as if it was still in full lockdown. Yet they remained completely excluded from being able to visit their relative.

151. The minister for social care, Kevin Stewart was supportive in trying to open up day services and support for our community of families. He was keen we named the local authorities who were not following government guidance. I'm not sure what impact he had; that tends to reinforce the lack of accountability at local authority level.

Financial Impacts

152. The extra Government funding in these times of emergency were so helpful. The fact that we could so quickly and easily access funds to deliver core services was so important for our families and carers and a lifesaver for us as an organisation.

153. It really enabled us to produce and deliver such a range of creative and innovative interventions which we would have otherwise struggled to achieve. But the same also goes for our other funders which also recognised the importance of being able to react quickly and that easier access to funds enabled our dynamic response to the crisis.

154. The pendulum effect now, though, is that funding streams are much more challenging, there are so many more obstacles to funding, especially the local authority funding process itself.

155. Compounded with the realities that there is now a greater need for third sector intervention because statutory services cannot recruit, nor have enough qualified staff, so they simply are not operating as they did pre-covid. Therefore, there are greater pressures on funding streams, not just caused by the cost-of-living crisis we are in now, but to fill the gaps left by absent statutory services.

156. We also received a lot of family feedback, which we shared with Scottish Government, especially relating to those in teaching and other local authority roles who had, essentially 24/7 caring responsibilities at home. As the restrictions eased, they were expected back to their working places, but there was no real understanding of the complex needs of their relative that they were caring for and the inherent risk of ongoing infections.

157. However, this was across the board where many people were expected back to their workplaces. There seemed to be a general lack of understanding surrounding the range of impacts upon them, from their caring role and having to deal with the complete withdrawal of care support services.

158. We have evidence from families that people who had successfully worked from home were then forced back into their office. They were so concerned that their exposure to lots more people would increase their own risk of being infected with Covid, which they would then bring home and risk cross contamination there. We had an example of where their employer was so inflexible that the family member felt compelled to give up their job, so they had to resign.

159. It's just tragic really. It's almost like we are all in it together, until we are not.

Lessons Learned

160. Technology was invaluable, thank goodness for Zoom. We could not believe the positive impacts it had on our ability to come together more effectively as a team as well as reach and support families and carers who would otherwise have been so completely isolated.

161. Our staff just did not stop problem solving, identifying ways to develop and engage with families and carers, they really pulled out all the stops.

162. It's the same for family carers too; they are so creative, so imaginative with solutions to the problems they encounter. They are so willing to pool that collective knowledge and wisdom, to share and develop it all, which we would share with our wider network of other families and carers.

163. We really did have an impact beyond Scotland and that was so valuable to help people in those communities to deal with the really challenging impacts of Covid.

164. The collaborative approach across a number of third sector organisations with the Scottish Government Disability teams was invaluable. Without that engagement, we really would have given up. We felt that somebody was listening, taking our feedback and experiences seriously and using it to influence positive changes to guidance for all our groups, which was just so important.

165. I feel, though, that we were ignored at the local community level. Whereas the first tier of Scottish Government did listen and engage with us, this did not translate into meaningful outcomes at the local level.

166. The Scottish Government Leadership Network, facilitated by very engaged civil servants was where we fed our findings into. This group was a lifeline for us, but I think this group struggled to influence Jason Leitch's group. So, again, we did feel eventually that though it was good to have this "in", it became clear that beyond that immediate engagement, we felt that we weren't being acknowledged and listened to.

167. National guidance was not followed, or advice given on how local services were to develop and adapt which had a dreadful impact on the physical health, mental health and emotional wellbeing of people with PMLD but also if their families.

168. The immediate withdrawal of Allied Health Professionals, day services and respite services, everything, all these health and social services which are intertwined, with no resilience or other contingencies, had a massive impact on our community. It caused an exponential risk to their overall wellbeing, more than the risk presented by Covid alone.

169. All our families and carers are such experts in infection control, routinely conducting their own array of risk assessments, but this was overridden and undervalued.

170. It was such a missed opportunity to not engage with those experts, they could really have got services back in, back to working with families and carers much more quickly than it did.

171. It really just reinforced that sense of abandonment and invisibility which haunted our community, and which still affects them all to this day, because services are still not operating as they did pre-covid. The impacts are dreadful and, in some cases, fatal.

172. In a lot of ways, nobody thanked our families and carers, properly, for what they did. It really does feel as though we were all in it together, until we weren't. But actually, for the families/community we support we weren't really ever all in it together. We have even had money withdrawn by one local authority which we strongly suspect is because we complained about a lack of day services. We, like the people we supported also felt really isolated.

173. Fundamentally, the biggest lesson is about listening; listening to families who are the experts. We learned so much from them about issues, solutions and how to get through it together. So, it's about that collective wisdom again; seek to understand and listen to actually hear what people with PMLD and their families are saying. We were listened to, but in the end, nobody heard us properly. By listening to understand you achieve more. There is also such a need for collaborative risk assessment to support our most vulnerable communities.

Hopes for the Inquiry.

174. I hope it makes the invisible visible.

175. If there is ever such an emergency again, should there be some weighting applied to the most marginalised/vulnerable in these times, so that they are thought of first?

176. PAMIS has four founding objectives one of which is "people with PLMD should receive all the support needed to realise their full potential." I believe that the wholesale closure of medical and social care services had an enormous impact on our group. Most will not recover from that. Unfortunately, the health of a number of people in our group deteriorated so much that they died earlier than would have otherwise been the case.

177. There must be accountability; how do we ensure that government guidance is not diluted, changed, or ignored such that there are thirty-two version of the truth, as each local authority chooses to interpret that national guidance.

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