

## **SCOTTISH COVID-19 INQUIRY**

### **OPENING STATEMENT ON BEHALF OF PROMOTING A MORE INCLUSIVE SOCIETY (“PAMIS”)**

1. As a Core Participant to this Inquiry, with leave to appear at the hearings on the impacts of Health and Social Care, PAMIS presents the following opening statement in accordance with the direction of Lord Brailsford dated 29<sup>th</sup> September 2023. As part of the opening statement PAMIS has included some photographs. PAMIS considers that it vital that there is a visible representation of the individuals that PAMIS represent, many of whom are non verbal.

#### **PAMIS/PMLD**

2. PAMIS has been in existence for 31 years, and is the only charity that supports, and works exclusively with, children, young people and adults with profound learning and multiple disabilities (“PMLD”) and their family carers. People with PMLD will have one or more of the following characteristics:
  - Physical disabilities that seriously limit their ability to undertake everyday tasks and usually restrict their mobility;
  - Sensory impairments with vision and/or hearing affected;
  - Communication is typically non-verbal, though some will have very limited speech;
  - Non-verbal communication will be expressed in a variety of ways;
  - Some communicative behaviour may challenge services; and,
  - Require one to one care over 24 hours, with some persons requiring two to one care.
3. The combination of intellectual, physical, and sensory difficulties is often compounded by significant health problems, including epilepsy, respiratory and nutritional difficulties. However, the abilities of those persons described as having PMLD vary considerably and not least because of the varied life experiences they may or may not have had.
4. Persons with PMLD make up one of the most marginalised, excluded and isolated groups in society. Many of them live at home with their parents, and family carers spend

on average 8.5 hours per day on basic caring tasks. Due to the multiplicity of their disabilities, they are often excluded from playing a full role in society because communities are not inclusive, or not inclusive enough. However, with the correct help, support and accessible resources, people with PMLD can and do take an active role in their communities.

5. PAMIS's founding objectives are that people with PMLD: are valued both as individuals and for the contribution they make to the community; should receive all the support needed to realise their full potential; have a right to a full life shaped by personal choice, abilities and needs which underlies all provision and policy affecting their lives. A further objective is that the knowledge and experience of family carers is recognised, and that their views are fully taken into account in service development. In furtherance of these objectives, PAMIS has continued to deliver on its four principal aims:
  - (i) give practical and emotional support, advice and training to the families of one of the most marginalised groups in society;
  - (ii) offer advice and information to professionals in social, education, health services and voluntary agencies regarding support for people with PMLD and their families;
  - (iii) contribute to and influence policy and practice in order to ensure families and their PMLD relatives have an optimum quality of life; and,
  - (iv) undertake research on specific aspects of health, education and social care which impacts on the lives of people with PMLD and to apply the outcomes in training and information sessions for family carers and professionals.

#### **Impact of the Covid-19 pandemic on people with PMLD**

6. The inequalities experienced by people with PMLD and their families were highlighted during the Covid 19 pandemic, and this period presented some of the most challenging times they have faced. PAMIS heard first-hand about its impact on people with PMLD, which left them feeling “abandoned”, “forgotten”, “invisible” and “not valued”. Specific examples include:
  - a high proportion of people not receiving shielding letters;
  - not having access to PPE;
  - the withdrawal of allied health professional services, day services and support services;

- the absence of guidance tailored to the needs of people with PMLD;
- the marked deterioration in the mental and physical well-being of individuals, with many losing skills which may never be regained;
- family carers whose relatives lived in alternative accommodation, such as residential care and supported living, being prevented from visiting to provide emotional and physical care, and in some cases not being able to see their loved one for over two years;
- the loss of respite / short break services which are a lifeline service for many PMLD families and the loss of which was devastating to families during Covid;
- families becoming exhausted; and,
- a lack of support leading some to consider suicide pacts.<sup>1</sup>

7. The Inquiry should understand that people with PMLD require multiple supports to ensure their dignity and quality of life. It is often a fragile framework. With the onset of the pandemic, all those supports were lost in an instant. Families were left isolated and alone, family life disintegrated and very few seemed to question that decision. Furthermore, people with PMLD still remain affected and have not recovered from the devastating effects of the pandemic, for example many have not had their full care packages properly re-instated, and some remain detached from allied health professionals. Some people with PMLD even lost their lives as a result of the absence of treatment and support in critical moments of their care. A specific example includes a young man whose equipment was not updated and caused further deterioration in his posture, which it is believed contributed to his premature death. These stories should be heard and lessons learned, so that they are never repeated. For many, the only help and support was provided by third sector organisations, such as PAMIS.

### **PAMIS's work during the Covid-19 pandemic**

8. On 23 March 2020, PAMIS rapidly moved to a virtual service, and in many areas, PAMIS was the key link for families to obtain PPE, advice, and guidance. PAMIS was

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<sup>1</sup> These issues were highlighted in the UK Covid-19 research 'Coronavirus and people with learning disabilities' study's website' available at: <https://warwick.ac.uk/fac/soc/cidd/covid19-learningdisability/results>

often their sole support. Within a very short time scale all members of the family support database had been contacted either by email or phone to check in and see what was required. PAMIS organised family carer support virtually, evening chats, social catch up, workshops, activities to do as a whole family including the PAMIS virtual disco, art, music, storytelling. In addition PAMIS carried out the following activities:

- the development of a multisensory resource to support people with emotional trauma;
- postural care, including online resources, webinars and training;
- sharing of the PAMIS digital passport, a flick through e-book to assist people with PMLD to communicate their needs to those around them;
- educational placements for health and social care students.

9. PAMIS was able to engage a large number of family carers in UK Covid 19 research, and a briefing paper was also prepared for Scottish Government highlighting actions to be taken<sup>2</sup>. While PAMIS considers that Scottish Government’s guidance was at times sensible, it found that inconsistent local interpretation meant that the overall meaning and objective was lost. Examples include:

- an inconsistent approach to the reopening of day services and respite facilities. In many cases, families felt that local authorities used the situation as an opportunity to close services without consultation;
- care packages were reviewed during Covid-19 despite the Scottish Government’s reassurance that this would not happen;
- inconsistent approaches to allowing family to visit relatives in a care home setting;
- lack of family involvement in risk assessments regarding loss of contact despite the Scottish Government’s guidance recommending such involvement; and,
- an inconsistent approach to accompanying people with PMLD into hospital and within ambulances despite a directive from the Scottish Government.<sup>3</sup>

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<sup>2</sup> ‘Coronavirus and people with learning disabilities, policy brief’, available at: [https://www.sclcd.org.uk/wp-content/uploads/2022/01/Coronavirus-and-people-with-learning-disabilities\\_Policy-brief\\_15.03.22.pdf](https://www.sclcd.org.uk/wp-content/uploads/2022/01/Coronavirus-and-people-with-learning-disabilities_Policy-brief_15.03.22.pdf)

<sup>3</sup> Scottish Government, *Hospital visiting: guidance for health boards* referred to in the Cabinet Secretary for Health and Sport’s letter to Local Authorities Chief Executives and NHS Territorial Board Chief Executives regarding social care in hospital dated 17 November 2020

## **PAMIS'S EXPECTATIONS FOR THE INQUIRY**

10. PAMIS's hope is that the Inquiry raises the visibility of people with PMLD and their unique contribution to Scottish society. PAMIS hopes that they are never again forgotten or abandoned in any future pandemic or public health emergency. PAMIS notes the thoughtful and humane approach taken thus far by the Inquiry Team and hopes that such approach will continue. For the first time, the organisation has felt *listened to* and *understood*, which is in stark contrast to how people with PMLD and those advocating on their behalf have felt up until this point. PAMIS hopes that the Inquiry Team will elevate the voice of one of the most vulnerable groups in Scotland and ensure that for those who do not yet know who they are, they will never be forgotten.
  
11. It will be crucial to establish what consideration, if any, was given to the impact of withdrawing the complex and specialist services from people with PMLD, what balancing exercise was carried out and what efforts were made to reinstate crucial services as the country came out of lock-down.

### **Understanding the impact**

12. For the Inquiry to fully understand the impacts of the response to the pandemic on persons with PMLD, PAMIS considers that it is vital that the Inquiry hears evidence from the following groups and individuals:
  - Individuals with PMLD of all ages, from every local authority and from all different types of accommodation and care settings;
  - Family members including parents, siblings, families who had babies with PMLD during the pandemic, those who had additional caring responsibilities, those who had relatives in care homes and other residential settings and those who lost loved ones during the pandemic;
  - PAMIS staff; and,
  - Social care staff within care accommodation.

Human-rights and equalities

13. PAMIS fully supports the Inquiry's intention to adopt a human rights-based approach to the Inquiry.
14. While the Inquiry is yet to make its human rights paper public, PAMIS submits that its approach should comply with the following principles:
- The investigative duty under Article 2 ECHR arises when the State may be in breach of one of its positive duties to protect life. Those positive duties include the legislative and administrative framework designed to provide effective protection for the right to life, systems in place to safeguard against risks to life, the duty to provide information to individuals whose life may be at risk, and, taking operational measures to safeguard a specific individual or individuals against risks to their lives which are real and immediate and of which authorities ought to be aware<sup>4</sup>;
  - Certain rights do not allow for any derogation, including Article 2, the right to life, (except in the context of lawful acts of war) and importantly Article 3 of the ECHR, the prohibition of torture and inhuman or degrading treatment<sup>5</sup>;
  - Articles 2 and 3 may be invoked in respect of severely ill patients and people with disabilities. Their exposure to illness and extreme levels of suffering may be incompatible with the State's positive obligation to protect life and prevent ill-treatment<sup>6</sup>;
  - Effective enjoyment of the right to family life is a benchmark of a modern democratic society. Significant restrictions to usual social and family activities may only be possible if they are established by law and proportionate to the legitimate aim pursued, including the protection of health<sup>7</sup>;

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<sup>4</sup> *Osman v United Kingdom*, [GC] app. no. (87.1997/871/1083), 28 October 1998, at [115]

<sup>5</sup> Council of Europe, *Respecting democracy, rule of law and human rights in the framework of the COVID-19 sanitary crisis: a toolkit for member states*, SG/INF(2020) 11, 7 April 2020.

<sup>6</sup> *Ibid*

<sup>7</sup> *Ibid*

- The State's failure to take into account the specific needs of persons belonging to a disadvantaged group may result in a finding of discrimination in contravention of Article 14<sup>8</sup>;
- The prohibition of discrimination may entail obligations to take positive measures to achieve substantive equality<sup>9</sup> ;
- The failure to treat different cases in a different manner may constitute unjustified discrimination<sup>10</sup>;
- States should take all necessary measures to ensure the safety and protection of people with disabilities in situations of risk<sup>11</sup>;
- Containment measures such as social distancing and self-isolation may be impossible for disabled persons who rely on the support of others to eat, dress and bathe<sup>12</sup>;
- There must be a sufficient element of public scrutiny to secure accountability in practice as well as in theory<sup>13</sup>;
- Public health emergencies must not be used a pretext for human rights infringements. Measures aimed at protecting people must be applied with strict respect for human rights obligations which include the enjoyment of fundamental rights and freedoms<sup>14</sup>; and,
- The victim's family or next of kin must be involved in the procedure to the extent necessary to safeguard his or her legitimate interests.<sup>15</sup>

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<sup>8</sup> *Horvath and Kiss v. Hungary*, app. no (11146/11), 29 January 2013

<sup>9</sup> *Cam v. Turkey*, app. no (51500/08), 23 February 2016

<sup>10</sup> *Nachova and Others v. Bulgaria*, [GC], app. no. (43577/98 and 43579/98) at [160]

<sup>11</sup> United Nations Convention on the Rights of Persons with Disabilities, Article 11. The UK ratified this Convention ratified in 2009. The Scottish Government intends incorporate this treaty into Scots Law.

<sup>12</sup> United Nations, Office of the High Commissioner on Human Rights, *Covid-19: Who is protecting the people with disabilities? – UN rights expert*, 17 March 2020 which refers to the declaration of the UN Special Rapporteur on the rights of persons with disabilities, available at: <https://www.ohchr.org/en/press-releases/2020/03/covid-19-who-protecting-people-disabilities-un-rights-expert?LangID=E&NewsID=25725>

<sup>13</sup> *Guiliania and Gaggio v. Italy*, [GC], app. no. (23458/02), 24 march 2011 at [304]

<sup>14</sup> Consultative Council of European Judges, *Statement of the President of the CCJE, The role of judges during and in the aftermath of the Covid-19 pandemic: lessons and challenges*, 24 June 2020, available at: <https://rm.coe.int/ccje-2020-2-statement-of-the-ccje-president-3-lessons-and-challenges-c/16809ed060>

<sup>15</sup> *Al-Skeini and Others v. United Kingdom*, [GC], app. no. (55721/07) 7 July 2011 at [167]

15. Similarly, the Inquiry should have regard to the provisions of the Equality Act 2010. All persons with PMLD have the protected characteristic of disability. PMLD has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities.<sup>16</sup>

16. As a result, PAMIS submits that the Inquiry must examine whether the Scottish Government, health boards and local authorities complied with their public sector equality duty (“PSED”) during the pandemic. The Inquiry must consider whether their policies, practices and decisions had due regard to the need to eliminate discrimination, advance equality and foster good relations between persons with PMLD and others who do not share that protected characteristics.<sup>17</sup> In doing so, the Inquiry should ask whether Scottish Government, health boards and local authorities complied with their PSED in substance, with rigour, and an open mind.<sup>18</sup>

#### The duty of candour

17. PAMIS recognises and supports the commitment of both the Chair and the Inquiry Team to carry out an exhaustive investigation into Covid-19 in Scotland in accordance with the terms of reference. PAMIS is committed to assisting the Inquiry in an open, constructive, and collaborative manner.

18. PAMIS believes that it is vital that all core participants, and especially public bodies, commit to doing the same. Many individuals, families and organisations have been failed in the past by public bodies not cooperating or acting with absolute candour. This Inquiry cannot allow the same to happen.

19. Accordingly, all core participants must commit and adhere to the principles contained in The Right Reverend James Jones’s *Charter for Families Bereaved through Public Tragedy*, namely to:

- Place the public interest above their own reputation;

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<sup>16</sup> Section 6 the Equality Act 2010

<sup>17</sup> Section 149, Equality Act 2010

<sup>18</sup> *Hotak v. Southwark LBC*, [2015] 2 WLR 134 at [75]



- Approach the Inquiry with candour, in an honest, open and transparent way, making full disclosure of relevant documents, materials and facts. The objective should be to assist the search for truth. They should be willing to learn from the findings of external scrutiny and from past mistakes;
- Avoid defending the indefensible or to dismiss or disparage those who may have suffered; and,
- Recognise that they are accountable and open to challenge.<sup>19</sup>

## CONCLUSION

20. PAMIS welcomes the beginning of the public hearings for the Scottish Covid-19 Public Inquiry and commends the Chair's and the Inquiry Team's commitment to ascertaining the truth. PAMIS is ready to contribute towards a process which is robust, exhaustive, fair and ensures accountability. Lessons can and must be learned so that suffering of persons with PMLD is avoided in future pandemics and public health emergencies.

21. Moving forward, PAMIS hopes that persons with PMLD and their families are involved as partners at a local and national level in developing appropriate policies, guidance, and solutions. This Inquiry represents an opportunity for that change to begin to materialise.

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<sup>19</sup> The Right Reverend James Jones KBE, *'The patronising disposition of unaccountable power'*. A report to ensure the pain and suffering of the Hillsborough families is not repeated, 1 November 2017, available at:

[https://assets.publishing.service.gov.uk/media/5a82c1cce5274a2e8ab5931d/6\\_3860\\_HO\\_Hillsborough\\_Report\\_2017\\_FINAL\\_updated.pdf](https://assets.publishing.service.gov.uk/media/5a82c1cce5274a2e8ab5931d/6_3860_HO_Hillsborough_Report_2017_FINAL_updated.pdf)



