

PAMIS

Promoting a More Inclusive Society

Background Information for the Scottish Covid-19 Inquiry

About PAMIS

PAMIS, promoting a more inclusive society (website: www.pamis.org.uk: <https://www.facebook.com/pamisscotland>), founded in 1992, is the only charity that solely supports children, young people (CYP) and adults with profound learning and multiple disabilities (PMLD) and their families to lead healthy, valued and included lives. PAMIS offers a range of projects and programmes including: family support services; education and development; research and practice development; inclusive culture and leisure; campaigns; information sharing and our library including the PAMIS multisensory stories; advice and registration of Scottish changing places toilets and resources to support digital inclusion.

This core work supports PAMIS's founding objectives that:

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

PAMIS has spent 31 years listening to and working with this group of people and their family carers. It has built research and practice that supports this group to be included and valued within society, albeit slowly and with much still to be done.

PAMIS is recognised nationally and internationally for the work it undertakes and has led the world in work in relation to areas such as bereavement and loss, emotional well-being, multi-sensory storytelling, inclusive culture and leisure, lifelong learning for people with PMLD and as the cofounder of the changing places toilet campaign.

PAMIS has continued to deliver on the four principal aims on which it was established. These were to:

1. Give practical and emotional support, advice, and training to the families of one of the most marginalised groups in society, i.e., people with profound and multiple learning disabilities (PMLD)
2. Offer advice and information to professionals in social, education and health services and other voluntary sector agencies regarding support for people with PMLD and their families.
3. Contribute to and influence policy and practice in order to ensure families and their PMLD relatives have an optimum quality of life.
4. To undertake research studies on specific aspects of health, education, social care that impact on the lives of people with PMLD and to apply the outcomes of such studies in training and information sessions for family carers and relevant professionals.

The PAMIS 10-year strategy builds on this, recognising that change takes consistency in messaging and action over time, and ensuring support, service, innovation, education, and development to support the most marginalised within our communities.

PAMIS delivers education and development opportunities to those supporting people with PMLD across sectors and communities, including health and social care workforce present and future, business tourism, architecture, and place designers.

PAMIS has built a model for education that supports family carers and people with PMLD as educators, delivering a range of training and development opportunities and co-training on courses such as the postural care training course, bereavement and loss and understanding communication and behaviour.

PAMIS actively engages with local and national government to amplify the voices of those it supports, and influences policy and provision across Scotland.

PAMIS Leadership

PAMIS is led by its Chief Executive Officer (CEO), Jenny Miller. The CEO leads the staff and all internal and external operational matters for PAMIS across Scotland. She leads on the development and implementation of strategy and is the driver of the PAMIS relationship with the Scottish Government and other stakeholders.

The CEO is heavily involved in research, practice development and training with partner agencies including universities and national Commissions. She acts to influence policy and practice nationally so that the PMLD community is seen and served. She is a lead for the public face of PAMIS.

The Covid pandemic presented unforeseen challenges and the CEO was responsible for leading PAMIS to a workspace where the organization could successfully deliver a service to this vulnerable community. She was also the conduit to the Government to share these challenges.

PAMIS has a Board of Directors led by the Chair, Pat Graham.

The Board led by the Chair has strategic oversight of PAMIS, its functions and direction. The Board exercises financial scrutiny. The Chair leads and supports the Board and supports the CEO in her endeavors.

The Chair is heavily involved in the training of partnership professionals and represents PAMIS on research projects, Scottish Government working groups and national NHS Trust initiatives.

As well as leading the Board, the Chair is the parent of a child with PMLD. PAMIS strives to represent with accuracy and authenticity the complex and varied needs within the PMLD community to the outside world and the Chair's own experience and broad knowledge of the collective lived experience of PMLD families distinguishes her contribution.

The CEO and Chair fulfil closely connected but distinct roles in PAMIS, each contributing complementary skills and expertise.

More about PAMIS

PAMIS is a national third sector organisation which employs professional staff across Scotland in a range of different local and national roles.

There is a team of Family Support Directors (FSDs) who have a presence across five health board and their corresponding local authorities/Health and Social Care Partnerships: Grampian – (Aberdeenshire and families in Aberdeen city), Greater Glasgow and Clyde (Glasgow City, East Renfrewshire, Inverclyde, Renfrewshire, East Dunbartonshire, West Dunbartonshire), Lanarkshire (north and South), Fife and Tayside (Perth and Kinross, Angus, and Dundee).

During the pandemic, FSDs provided support nationally to more than 700 families across matters including access to services, withdrawal of services

including Allied Health Professions, day services and respite care, and changes to care packages.

PAMIS also employ a number of staff in national roles including a lead for digital and health, inclusive culture and practice development, inclusive communities and national priority projects such as postural care. This team were key in the pandemic developing resources for families, practitioners and organisations including online multisensory resources, online courses to support postural care and moving and handling, resources to support emotional wellbeing and the roll out of the PAMIS digital passport.

The **PAMIS digital passport** –

<https://pamis.org.uk/services/digital-passports/> - a flick through e-book based on the paper communication passport are used across the UK and beyond in a wide variety of settings by anyone who needs support to communicate their needs to those around them. The most important aspect of the passport is its relevance and easy to use structure, its unique ownership, and the lead taken by people with profound and multiple learning disabilities and their family carers in its development. This tool was essential during the pandemic especially if unknown carers became involved, family carers became unwell or there was any emergency care required.

During the pandemic PAMIS provided free training and support to a number of organisations to support the development of the passport for a range of client groups. PAMIS continued to support its families to develop them, and had a range of health and social care students who, as part of their practice placement, developed these for families.

PAMIS thus has access to valuable evidence of the pandemic, the policy response to it, and crucially, the impact thereof on some of Scotland's most marginalised and vulnerable families.

More about people with PMLD

People with PMLD clinically share characteristics which lead to significant challenges for them and those who support them.

For people with PMLD, their prime disability will be **profound learning (intellectual) disability**. The causes are many and varied. Whatever the cause, and this sometimes goes undiagnosed, their development as children and adults is **severely** constrained.

People with profound learning (intellectual) disability and additional complex multiple disabilities (PMLD) are a diverse group of individuals with their own personalities, preferences, and ways of communicating.

The abilities of those described as having PMLD vary considerably, not least because of the varied life experiences. They are a marginalized group in society. Due to the multiplicity of disabilities, people with PMLD are often excluded from playing a full role in society, primarily because our communities are not inclusive, or not inclusive enough.

Profound means deep, intense, wise, requiring great insight or knowledge and although many people with PMLD have significant areas of disability, as described, they also have unique areas that never cease to surprise those who care and work with them.

Clinical description

The clinical description below is the science, but a clinical description misses the unique contribution people with PMLD make to the lives of others- not least in what they are able to teach about how to care, how to act with compassion and how to make human connections.

All with PMLD will have a profound learning disability and one or more of the following:

- Physical disabilities that seriously limit their ability to undertake everyday tasks and usually restrict their mobility, with the majority being lifelong wheelchair users.
- Sensory impairments with vision and/or hearing affected.
- Communication is typically non-verbal, though some will have very limited speech.
- If non-verbal, all have the capacity to communicate in a variety of non-verbal ways.
- Some will also have communicative behaviour which may challenge services.
- The majority will require 1:1 24-hour care and many will require 2:1 care provided. **Healthcare needs are extensive and complex and may be life threatening.**

Areas of particular challenge relate to:

- Epilepsy - Intractable epilepsy and the administration of emergency/rescue medications
- Respiration
- Delivery of invasive procedures
- Eating and drinking (dysphagia)

- Invasive procedures including gastrotomy, nasal pharyngeal airway, tracheostomy, baclofen pump.
- Bair hugger systems for temperature control
- Postural care
- Contenance
- Sensory impairments including being registered blind and hearing impaired but also tactile sensory issues and many have sensory integration needs.
- Hoisting for moving and handling transfers
- Special diets

Services for people with PMLD

People with PMLD and complex healthcare needs require high packages of care, which will often require intensive support on many levels. Specialised input from education, health, social care and housing is the norm and highlights the complex packages that must be negotiated. This in turn takes extra time and effort which can be exhausting for family carers, often already providing high levels of unpaid care. This was and is particularly so for many families during and since the pandemic.

PAMIS advocacy and the Inquiry

PAMIS wishes to amplify that voice of lived experience to properly account for Scotland's experience of the pandemic.

PAMIS intends to assist the Inquiry in developing a factual narrative informed by the experience of all who experienced the pandemic, informed by a wealth of contemporaneous evidence.

PAMIS will actively engage with the Inquiry to ensure that lessons are learned from the lived experience of the families it represents. That engagement will strengthen the Inquiry's recommendations, ensuring Scotland's future policy respects, protects and advances the rights of everyone, equally.

The pandemic and the PMLD community

PAMIS supported more than 700 families affected by PMLD across the whole of Scotland during the pandemic.

PAMIS can evidence that families feel key decisions were made for them, rather than by or with them, that families were not adequately consulted, and that their voice has yet to be heard.

Issues reported by families:

- their relative not being included on the high risk register even with several of the high-risk conditions.
- withdrawal of all services.
- withdrawal or reduction of respite.
- difficulty accessing PPE.
- isolation and poor communication with services and local and national government/authorities.
- changes to care packages to the detriment of the individuals with PMLD and their carers.
- no or reduced day services.
- no or reduced access to allied health care professionals vital to the health, development, and wellbeing of individuals with PMLD.
- buildings closure.
- inadequate equipment.
- staff shortage in day services, supported accommodation and residential care.
- denial of appropriate support for a relative being admitted to hospital.
- limited or no adult social workers appointed for transitions to adult services.
- lack of employer support for intense family carer role.
- denial of access to provide personal, emotional, and physical care to relatives in supported accommodation or care home.
- reduced life expectancy, reduced mobility; permanent postural damage and other physical and developmental damage regression.
- deteriorating mental and emotional health of relative with PMLD.
- deteriorating mental and emotional health of carers, suicidal feelings of carers.

PAMIS response

PAMIS played a significant, direct role supporting families through the pandemic and engaging with national government to address the systemic and systematic challenges they faced.

For example, PAMIS engaged with the Scottish Government by providing (initially weekly) feedback about the issues that this group were facing.

PAMIS hosted focus groups with families and Scottish government officials to highlight issues but also to provide insights from families regarding solutions.

PAMIS supported family carers to participate in various COVID related research projects.

PAMIS co-hosted a family carer webinar with two other organisations to highlight the issues for families of children and young people with complex healthcare needs- and invited Jason Leitch to attend and answer families queries.

In addition, PAMIS supported the development of resources, and of education for health and social care practitioners and family carers. This included the resource to support the roll out of vaccines for children and young people.

Roll out of the PAMIS Digital passport as mentioned previously was essential during the pandemic especially if unknown carers became involved, family carers became unwell or there was any emergency care required.

PAMIS, through its emotional wellbeing projects including art, music, and multisensory storytelling and utilising the digital passport gathered audio, visual and other media evidence of the impact of the pandemic on those it represents, including many who are nonverbal and otherwise face significant difficulty communicating.

Post pandemic

PAMIS understands that families continue to be significantly impacted by the consequences of the pandemic and the policy response to it. Individuals live with the consequences of withdrawal of support services during the pandemic, exacerbated by continued failure to make adequate provision. The consequences of the pandemic continue to be felt and action is needed to protect vulnerable families across Scotland.

Given the scale of its casework, PAMIS has access to a significant volume of contemporaneous evidence including documents, research outputs and communications. It will be able to put this evidence before the Inquiry to ensure that the Inquiry's factual narrative is robust and that its investigation fully documents the unequal impact of the pandemic.

Throughout its existence, PAMIS has worked to ensure that families are heard in policy affecting them. Participation in the Inquiry will be driven by those families and centred on their experiences and wishes. PAMIS has close relationships with

families across the country and will encourage and support them to engage with the Inquiry.

Throughout the pandemic, families engaging with PAMIS said they felt **invisible, abandoned and ignored**. The voices of those families must now be heard and must inform the Inquiry's recording and recommendations.

The Inquiry is enjoined to consider the unequal impact of the pandemic, and PAMIS can aid the Inquiry in fully ventilating the complex and multifaceted impact on some of the most vulnerable members of Scottish society.

PAMIS represents an exceptionally vulnerable cohort which shares at least the protected characteristic of disability within the meaning of the Equality Act 2010; and members are entitled to non-discrimination in the enjoyment of their rights, within the meaning of article 14 of the European Convention on Human Rights.

PAMIS considers that national policy and local provision infringed on those rights, and unfairly and unreasonably subjected disabled persons to rights violations and unlawful discrimination. It is uniquely placed to assist the Inquiry in fully ventilating those concerns and developing a reliable factual narrative, as well as sound recommendations for future, rights-respecting policy responses to civil emergencies.

www.pamis.org.uk