

PE1548/J

Petitions Committee
Scottish Parliament
Edinburgh
EH99 1SP

15th May 2015

PAMIS response to petition number PE015648: (National Guidance on restraint and Seclusion).

Dear petitions committee

PAMIS are aware of this petition currently going through the petition process and would like to take this opportunity to comment.

This response includes a description of PAMIS and the people we support; comments on why guidance is necessary; and recommendations for the way forward. The response has been designed in this way to ensure that there is no misunderstanding of the individuals we are referring to and to aid the planning of future actions that might be undertaken by the Scottish Government as a result of the issues raised in this petition. It is crucial that all policy and guidance reflects that children with profound and multiple learning disabilities have the right to a full life, shaped by personal choice, abilities and needs and that they receive all the support needed to feel valued and to participate fully in everyday life. While, like the parents we acknowledge that the Scottish Government wants to make Scotland a safe place for all of the country's children, regardless of disability we feel that the question of national guidance on restraint and seclusion in schools is not being adequately addressed and offer this response as an aid to opening dialogue on how working together with families and experts in positive behaviour support, we can improve the lives of children with profound and multiple learning disabilities (PMLD).

PAMIS is the only charity in Scotland that works solely with people with profound and multiple learning disabilities (PMLD) and their family carers. Established in 1992 it provides support for people with PMLD their families and those who work with them. PAMIS provides research, education and the development of best practice in the field of PMLD and we campaign for and promote a more inclusive society for some of the most excluded and marginalised people.

In our experience there is often a distinct lack of understanding about who this group of people with PMLD are. People with 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. They do, however, share a number of characteristics that make this term appropriate and which leads to the challenges they and those who support them face. Their prime disability will be profound learning (intellectual) disability. The causes are many and varied. All have had some form of damage to their brain and central nervous system. This may be caused by injury before, during or after birth, by genetic factors, by infection to them or their mother, or by accidental or non-accidental injury. Whatever the cause, and this sometimes goes undiagnosed, their development as children and adults is severely constrained. Few achieve the cognitive and communicative abilities of a two year old, and clinically they are described as having an intelligence quotient less than 20 (IQ<20), hence "*profound learning disability*". The physical and sensory disabilities that arise from damaged brain function will also restrict their interaction with the world (the "*multiple disabilities*" referred to) making them highly dependent on others to ensure that they have the opportunity to experience the valuable things of life that others take for granted. The majority will be life-long wheelchair users. The combination of intellectual, physical and sensory difficulties is often compounded by significant health problems, including epilepsy, respiratory and nutritional difficulties, resulting in many being fed non- orally.

PAMIS as part of their family support role within Tayside have been supporting the families concerned with this petition. They have also been involved in a range of approaches to support families, professionals and other sectors to recognise the specific, complex and often misinterpreted communication of people with PMLD. They recognise, along with leading researchers in the field, that people with PMLD will often communicate in ways that can be misinterpreted as negative behaviours as opposed to communicative problems. If individuals supporting people with complex communication problems are aware and understand the function of challenging behaviour then incidents of behaviour that is reported as challenging will be less likely to occur. However misinterpreted and handled in a negative and punitive way it might lead to challenging and distressing outbursts.

PAMIS is concerned that there appears to be a limited understanding of the children we are referring to by some of the senior figures within key organisations such as COSLA. It is apparent through their response to the petition that they do not understand the complexity of this group of people, who have serious developmental delay and cognitive problems that will not enable them to respond to the mainstream policies being suggested.

Suggested short term recommendations for improvement:

- *PAMIS* would expect to see the formation of a Short Life Working Group
- We would like to highlight to the Scottish Government that the matter of National Guidance and the problems raised in this petition should be dealt with separately and that the development of a sub group of the Scottish Advisory Group on Relationships and Behaviour in Schools (SAGRABIS) is inappropriate and not the correct body to undertake this process for the reasons mentioned in the parents response.
- There needs to be robust understanding and monitoring of the risk assessment processes and procedures as parents have reported that in many cases risk assessments have never been undertaken.
- The importance of including the Care Inspectorate in any future development around ensuring adequate inspection of procedures and protocols relating to children's health, safety and welfare cannot be overemphasized.

Suggested longer term recommendations for improvement

- *PAMIS* would suggest that people with PMLD should not be considered within a mainstream control and restraint policy unless the whole approach is restructured and starts with a framework to support positive communication approaches, building on a positive behavioural approach.
- *PAMIS* would also suggest that a multidisciplinary team approach which places the person with PMLD and their family at the centre is imperative. In addition organisations, and the staff within, working with this group of people require to be reflective; to be able to learn from incidents; have structured support and supervision and ongoing personal and professional development to ensure that policies and learning is translated into practice. Staff should also participate in cross agency evidence based learning and development that promotes a collaborative, positive approach to the support and development of people with very complex needs.
- Where there are incidents recording and reporting is key, as is following a recognised and evidence based approach to learning from a significant event. There are several approaches and one that might suit this context would be a values based reflective event analysis – (<http://www.knowledge.scot.nhs.uk/vbrp.aspx>). However none of this will provide a change to approaches if there is not the staff governance underpinning a framework – this must include regular and appropriate support and supervision.
- The schools inspections should also ensure that there is a specific team that looks at the significant event analysis and subsequent actions. An approach to these schools reviews that includes independent experts on positive

behaviour support and parents would be beneficial and make for a more transparent approach. This was particularly successful in review of learning disability services a few years ago by NHS Quality Improvement Scotland – now Health Improvement Scotland.

- Again and as highlighted above: the importance of including the Care Inspectorate in any future development around ensuring adequate inspection of procedures and protocols relating to children's health, safety and welfare cannot be overemphasized.
- *PAMIS* suggests that it is not helpful to have conflicting policies and that there should be a national, evidence based approach. This will promote best practice and also provide supervision and support for education across Scotland. It will also enable preregistration teaching qualifications to incorporate best and appropriate practice.

Conclusion

PAMIS acknowledges that teaching staff must at times feel isolated and vulnerable and that at times of stress and strain approaches that do not truly reflect the teaching profession are adopted. Understanding the complexities of an individual child with no verbal communication and limited cognitive ability takes a huge amount of time and a skill set that is not currently specifically taught within a teaching qualification. This makes it all the more important to provide additional support through a comprehensive and integrated team, and again with the child and the parent carer at the core.

PAMIS would like to offer access to a range of resources that they could contribute to the support and development of education staff. The *PAMIS* digital passport provides an instant access to the communication and health needs of a specific child as well as housing the positive behavioural support plan that highlights setting events, key triggers and suggested strategies to decrease incidents that could lead to behaviour escalating and becoming a serious challenge. There are some excellent examples of how successful this has been and *PAMIS* suggests that there is a review of how these measures can be incorporated into the schools where children with complex needs are based.

An obvious suggestion would be to support and deliver an ongoing programme of positive behavioural support training which includes parents as course tutors. *PAMIS* would like to be involved in the development of any proposed training package.

Finally given the varied responses and an apparent lack of understanding by some bodies regarding the needs of people with profound learning disabilities *PAMIS* joins the parents in suggesting that a national reference group be set up to address the

issues, design a framework and consider a collaborative way forward that will support some of Scotland's most vulnerable children.

Yours faithfully

Jenny Miller
CEO PAMIS