

PE1548/JJ

PAMIS submission of 31 August 2017

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.

PAMIS reiterates everything that we stated in our 2015 response to the petition at that time and welcome the changes within the new guidance Included and Engaged part 2, however we feel this guidance does not provide clear guidelines for staff supporting children with profound and multiple learning disabilities and those with complex communication difficulties. If the foundation for schools, learning establishments and education authorities is a whole school ethos of prevention, early intervention and support against a background which promotes positive relationships, learning and behaviours; as stated in the new guidance, then surely the starting point has to be that staff providing this environment have access to adequate learning and development that enables them to do so as effectively as possible for every child. Getting it Right for Every Child (GIRFEC) takes a holistic approach to the well-being of the child or young person and their families yet in the guidance although the wording has been amended to remove terminology such as “safe space” and does not make direct reference to an isolation room or offer a definition of a safe space, it nevertheless fails to highlight that this practice is unacceptable and morally wrong. In doing so the guidance fails to appreciate the complexities that the children and young people experience. There are records on the number of exclusions, the number of restraints, (although arguably these are not always recorded and reported in practice) the number of injuries caused through restraint and seclusion practices but nothing on the trauma this causes to children and young people who experience this or the support that is available to them following such incidents.

PAMIS believes that the Scottish Government should lead the way in providing guidance that emphasises the use of current Co-ordinated Support Plans (CSP) and other recording systems used within education to make sure every child has an individual profile that represents them as a whole. Information such as:

- sensory assessments
- communication assessments
- functional vision assessments
- any other health related assessment required, such as seating etc.
- knowledge from the family carer and health professionals that know the child well should all be included, providing a complete profile of every individual child.

This surely must form the basis of any child’s plan and would be a core element in understanding the child or young person and be a crucial part of any early intervention programme yet sadly it is not the case for the majority. PAMIS reiterates the recommendation for improvements mentioned in our petition response in 2015.

Suggested longer term recommendations for improvement (2015 response)

- 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.

We welcome the fact that the new guidance has attempted to improve the current situation within Scotland’s schools with regards to improving the educational experience for children with Special Education Needs. We feel however, that it fails to provide the detail necessary to help disseminate information that could better

contribute to the understanding, education and teaching of children with special educational needs.

Conclusion: In 2016 the UN Committee on the Rights of the Child recommended that the use of isolation rooms be abolished. PAMIS supports this recommendation. However in addition we recommend a robust educational framework that supports everyone involved in the education and care of the child to understand their specific and unique communication and emotional needs and to implement early positive interventions strategies.