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## Running head: Invasive procedures and people with PIMD

### **PAMIS Investigates Invasive Procedures in Scotland**

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The health needs of people with profound intellectual and multiple disabilities are complex and a majority may require at some time, some form of invasive medical procedure to ensure their well-being. Barriers to the administration of such procedures are prevalent, while issues concerning consent and capacity present further difficulties to the paid carer. The voluntary organisation *PAMIS* is engaged in a national research project supported by the Scottish Government to determine what leads to problems of delivery of invasive procedures in Scotland. Preliminary findings from professional and carer workshops are presented and the objectives of a national postal survey described. A process of dissemination and consultation will then be initiated with a view to ensuring greater consistency of policy and practice throughout Scotland leading to greater equity and effectiveness of practice. Such measures will enhance the well-being of people with PMLD and increase the confidence and peace of mind of both family carers and paid carers.

#### Introduction

People with profound intellectual and multiple disabilities (PIMD) present with a range of complex and significant health care needs. As a consequence many require a diverse range of invasive health care procedures in order to maintain their health and well being. Among such invasive procedures are for example:

1. The administration of rectal anticonvulsants for the management of epilepsy
2. The management of baclofen implants for spasticity
3. Ventilators and tracheal suction for the management of respiratory disorders
4. The management of non oral feeding
5. The management of tracheotomies.

Despite the evidence of the range of health needs and clear government policy frameworks directed at enabling all people to live inclusive and independent lives in the community (Department of Health, 2009; Scottish Executive, 2000), significant variation and challenges exist in enabling this to be a reality for people with PIMD. This lack of clarity leads to particular challenges in relation to the delivery of invasive procedures in non-healthcare settings. This is supported by MENCAP'S *Death by Indifference* enquiry report (Mencap 2007) and a number of other

reports from across the UK, notably: *Healthcare for All* (Department of Health 2008), *Equally Well* (Scottish Government 2008), the *Same as You?* (Scottish Executive 2000), *Valuing People Now* (Department of Health 2009) and, the recommendations of a number of Fatal Accident Inquiries in Scotland, notably Mauchland (Dunbar 2003) and Donnet (Davidson 2007). Disparities in practice in this area need to be addressed and standardised implementation of policies and procedures need to be in put place to ensure that the needs of people with PIMD are met effectively in the future.

There are also significant ethical issues that need to be considered in the context of the capacity of people with PIMD to consent to treatment. Such ethical issues need to be viewed within the context of the Scottish legal system with attention paid to the Welfare Guardianship orders under the *Adults with Incapacity (Scotland) Act 2000*. These orders allow appointed guardians to act on behalf of people lacking capacity. When functioning correctly the Welfare Guardianship order ensures that the issue of consent is addressed and allows treatments and interventions to be undertaken appropriately. Although a framework addressing the issue exists in Scotland, there appear to be different approaches, across the country, in relation to the implementation of invasive procedures.

### **The Invasive Procedures Research project**

In response to these imperatives *PAMIS* has been funded by the Scottish Government to carry out research on the issue of invasive procedures in Scotland. A project group has been established to support the *PAMIS* research team in undertaking the research, and this is supported by a national expert reference group made up of practitioners, research workers and family carers.

The work is being undertaken in two related phases, first a consultative conference establishing the views of a wide range of stakeholders, and second, a national postal survey of views and practice.

### **Invasive Procedures: Breaking barriers and achieving control for people with profound & complex disabilities**

This conference was held in Dundee June 2009. Delegates from a wide range of social, education and health care backgrounds, as well as family carers, attended. Experts provided evidence on a range of issues and a series of workshops identifying the views of practitioners and carers was held. Possible solutions for the future were considered.

A wide range of issues was identified by the delegates (Hogg et al., 2009). Models of good practice as well as barriers to the effective delivery of invasive procedures were identified, including:

1. lack of training of staff required to implement the procedures
2. poor communication across professional groups and agencies
3. legal and liability issues in relation to non-health care practitioners undertaking invasive procedures
4. absence of clear operating procedures through failures of senior management to take a decisive leadership role.

Recommendations included:

1. the need to undertake an audit of training and resource requirements
2. identification of the transferability of skills to optimise effective delivery
3. development of joint collaborative training programmes across health, social care, the independent sector and with family carers
4. identification of the training needs of family and paid carers to deliver invasive procedures.

It was also recognised that there is a need to commission a review of the legal position regarding the delivery of invasive procedures and to clarify the role of Welfare Guardians when consenting to

invasive procedures for those without capacity. Poor communication was a theme that was identified throughout the workshops particularly across agencies at the time of transition between services. The workshops highlighted the need for continuity of care across the life span and for health services to ensure that there are protocols in place to support this. It was agreed that *PAMIS* has a key role in the effective dissemination of best practice.

The findings from the conference and the research will inform best practice and continuity of care in the future.

### **The national postal survey of views and practice in relation to delivering invasive procedures**

The Invasive Procedures Survey is being undertaken by *PAMIS* and the White Top Research Unit, University of Dundee. The questionnaire has been distributed throughout Scotland to family carers and professionals and data are at present being analysed. These survey findings will be integrated with those arising from the conference.

### **Conclusion**

Completion of the national survey will complement and elaborate the recommendations made at the conference leading to recommendations the Scottish Government. A process of dissemination and consultation will then be initiated with a view to ensuring greater consistency of policy and practice throughout Scotland leading to greater equity and effectiveness of practice. Such measures will enhance the well-being of people with PMLD and increase the confidence and peace of mind of both family carers and paid carers.

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Scottish Government (2008) *Equally Well: Report of the ministerial task force on health inequalities*. Edinburgh: Scottish Government.

## References for the following article by John Shields page 11

### Some useful References & Resources provided as part of the Workshop Participants' Pack:

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**RNIB** produces a range of Factsheets and Information. Leaflets on all aspects of visual impairment. [www.rnib.org.uk](http://www.rnib.org.uk) and a journal called - **Insight: supporting blind and partially sighted young people** which contains lots of useful articles. *PAMIS* subscribes to this journal and copies are available in the library.