# Invasive Procedures: Minimising Risks and Maximising Rights

## *Improving practice in the delivery of invasive procedures for people with profound and multiple learning disabilities*

## Project Report and recommendations

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# Acknowledgements

## The Right to be Ordinary

“All people should have the right to be ordinary. When this right is compromised due to illness, disability or caring responsibilities, trying to be ordinary becomes extraordinary or special. All people deserve the right to be able to access choice, freedom and opportunity - all people deserve the right to be ordinary.”

Isobel Allan parent carer

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## Summary

Lack of equity in health care for people with learning disabilities has become an increasing concern with respect to national policy in Scotland (Scottish Executive 2002), while research has shown that this situation exists at all levels of the health care system (Hogg 2001). People with profound and multiple learning disabilities have been shown to be particularly vulnerable to poor health and health care provision, disadvantaged by complex conditions affecting their neurological state, their physical conditions, ability to eat and drink (dysphagia) and their respiration. As well as the detrimental impact of this multiplicity of conditions on their quality of life and that of their families, mortality is well in excess of other people with learning disabilities and the wider population, with over 20% of children and adults dying prematurely in any 10 year period (Hogg et al, 2007).

Several specific health care needs of children and adults with profound intellectual and multiple disabilities require intensive and regular intervention. With respect to *neurological problems*: epilepsy may be managed through the administration of Rectal Diazepam and/or Midazolam through the administration of buccal/nasal administration; severe spasticity may require Baclofen implants to alleviate spasms, while dysphagia may necessitate non-oral feeding (gastric and nasogastric) and respiratory problems may have to be dealt with through the use of ventilators and deep suctioning to maintain breathing.

These and other health care procedures are widely viewed as highly invasive, and, and there is evidence from a number of sources that their delivery can be problematical, contributing to the lack of equity noted above. The present study set out to identify which conditions are viewed by family and paid carers as being invasive, and the extent to which they judge that there are specific barriers to their delivery that lead to the adverse consequences. A questionnaire survey was undertaken with the principal aims of the study being to:

I. determine, from the perspective of paid and family carers as to what constituted an invasive procedure

II. establish the extent to which barriers exist which precluded the delivery of such procedures in service settings and what these barriers were

III. identify ways in which barriers may be overcome, and:

IV. more broadly, to describe examples of good practice in which barriers have been overcome

The survey was conducted in Aberdeen, Aberdeenshire, Angus, Dundee, Edinburgh, Fife, Glasgow, Highland, Orkney, Perth and Kinross, Shetland, South Lanarkshire and the Western Isles. 200 care settings were approached including: adult resource centres; community services; supported accommodation; schools and colleges; residential and nursing care homes;

and respite facilities. In addition, family carers were also invited to complete the questionnaire.

Pilot work led to the identification of 20 procedures that might be considered invasive. Respondents were asked to judge which they considered invasive, and which barriers they considered made difficult or precluded the delivery of each procedure. They were also invited to comment on their judgements and provide illustrations. The invasive procedures were: 1 Nasogastric tube feeding; 2 Gastrostomy; 3 Jejunostomy; 4 Tracheal suctioning; 5 Tracheal tube replacement; 6 Postural drainage; 7 Nebulising; 8 Oxygen delivery; 9 Short-term intermittent ventilation; 10 Long-term intermittent ventilation; 11 Manual bowel evacuation; 12 Delivery of enemas; 13 Delivery of suppositories; 14 Colostomy/IIleostomy care; 15 Urethral catheterisation; 16 Supra–pubic catheterisation; 17 Delivery of pessaries; 18 Injections; 19 Applying skin creams; 20 Oral/Nasal suctioning. There was highly significant agreement as to whether a given procedure was invasive, despite the lack of any formal definition of this term. In addition, agreement on their relative invasiveness between paid and family carers was also highly significant.

Barriers considered in relation to each procedures were: 1 Limited staff resources (insufficient time available to administer procedure); 2 Staff competence (Staff lack the necessary training to administer the procedure); 3 Staff attitude (Staff do not consider the task comes within their job specification whether competence or not); 4 Service agencies' policies and operating procedures; 5 Service agency commissioners' operating procedures; 6 Consent issues; 7 Care plan precluding a service provider administering an invasive procedure; 8 Union interventions; 9 Health and safety.

The percentage of both paid staff and family carers reporting that one or more of these nine barriers precluded or made difficult the delivery of each of the 20 procedures was computed, and written comments coded with respect to both difficulties and possible solutions. The findings demonstrated that at all levels of the system, delivery of such procedures can, in varying degrees, be obstructed by one or more of the barriers. All barriers explored were to some extent cited by some staff members as obstacles to the delivery of every procedure, though this effect was strongest for the procedures judged most invasive. Lack of staff competence and staff attitudes were most strongly cited as significantly precluding the delivery of a number of procedures, particularly those regarded as most invasive. Although competence and attitude were implicated as barriers, it is important to emphasise that wider factors such as policy and union interventions might set the conditions for staff's inability to deliver a procedures.

A corollary of these findings is that in some facilities in Scotland, all procedures *are* being delivered unobstructed by these barriers i.e. it *is* possible to make effective provision in educational, day service and other facilities. Specific examples of good practice are cited. Nevertheless, where barriers do preclude delivery, the impact on the individual with profound and multiple learning disabilities and their family is profound, as reported in family

carers' written comments of. Non-delivery of a procedure by staff could lead to anxiety and lack of confidence on the part of family carers, exclusion from services, and demands on family members to undertake the procedures themselves.

In general, family members cited fewer barriers than did staff. In part this may be lack of awareness of wider issues in service delivery, e.g. the role of commissioners, but as pointed out by some of them, *family members deliver all of these invasive procedures in their own homes year in and year out*. Family carers emphasised the importance of their involvement in both training staff and care planning.

Recommendations for action to improve the delivery of invasive procedures are made ranging from action to be taken by the Scottish Government through to the development of improved practice in individual facilities. Each recommendation details an aim, who has responsibility for implementation, validation of its effectiveness, the intended outcome, and the timescale for implementation. The report emphasises that the recommendations should be seen as interdependent and integrated into a coherent strategy. We conclude by suggesting that following discussion with the Scottish Government and relevant organisations, the report recommendations are integrated into a national strategic plan with implementation overseen by the Scottish Government or a relevant delegated body.

In addition to this summary and the main report, an executive summary is available (Garrard et al 2010).

# 1 Introduction

The health care needs of people with learning disabilities have come increasingly into focus through both policy statements (Scottish Executive 2002) and research (Schrojenstein et al 1997). For many individuals the conditions that lead to high levels of health care needs are multiple and complex (Hogg 2001). This is nowhere more so than for those with profound and multiple learning disabilities. People with profound and multiple learning disabilities typically have serious neurological damage resulting from trauma or genetic causation leading to two-thirds of people with profound and multiple learning disabilities having epilepsy (Hogg, 1992) and severe physical disability (Kobe et al, 1994), principally cerebral palsy, with resulting postural problems such as contractures and scoliosis, as well as extremely limited movement (Goldsmith and Goldsmith, 2000). In addition, muscle wastage occurs due to lack of movement and absence of weight bearing activity. Respiratory problems are also a central concern as they are the single largest cause of mortality for this group (Juhlberg et al, 2004; Hogg et al, 2007). A further challenge to carers and health professionals is difficulty in eating and swallowing, i.e. dysphagia, leading to nutritional difficulties for people with profound intellectual and multiple disabilities and resulting in their being significantly underweight (Kennedy et al, 1997).

In Scotland, this state of affairs has led the *Same as You Implementation Group* identifying ways in which the health care of people with profound intellectual and multiple disabilities may be improved and their well-being increased. Their health status also falls clearly within the concerns and strategies expressed in the Scottish Government's recent document, *Equally Well: Report of the Ministerial Task force on Health Inequalities* (Scottish Government 2008). Here the special health care needs of people with learning disabilities are fully acknowledged. In particular attention is drawn to vulnerable groups for which the need: *"…to target and meet the needs of those most at risk of poor health… (and)… to prevent problems arising in future…"* (p. 3).

Central to realising this recommendation for people with profound and multiple learning disabilities and their family and professional carers, is the effective and humane delivery of a wide range of invasive health care procedures to address the complex of difficulties in health noted above. These include:

(i) With respect to neurological problems: epilepsy sometimes must be managed through the administration of Rectal Diazepam and/or Midazolam buccal/nasal administration. Severe spasticity may require Baclofen implants to alleviate spasms.

(ii) Respiratory problems may have to be dealt with though the use of ventilators and deep suctioning to maintain breathing.

(iii) Dysphagia leads to non-oral feeding (gastric and nasogastric).

There is no agreed objective definition of a health care procedure as "invasive", and in the present study we have taken a pragmatic approach by inviting practitioners and family carers to indicate which health-related procedures they regard as "invasive". As we shall see, there is considerable agreement on the extent to which a given procedure may be viewed in this way, providing a firm basis for the survey described. It should also be noted that in the wider literature the term "invasive procedure" refers to measures taken to resuscitate a person (Henderson & Knapp 2005), interventions not considered in the present study.

There are two key issues related to the delivery of invasive procedures as identified here.

First, staff responsible for people with profound and multiple learning disabilities must be fully trained in these procedures and permitted to administer or carry them out when required. Execution of these procedures by social care staff remains a contested area, with some staff refusing or not being allowed to carry out one or more procedures, leading to people with profound intellectual and multiple disabilities being denied services (Garrard et al 2009)

Second, availability of the procedures in a wide range of settings is essential, including school or adult day facilities, residential settings and respite provision. There is clear evidence to suggest that people with profound intellectual and multiple disabilities are being denied services in such setting because of unwillingness to administer invasive procedures (Garrard et al 2009).

Across Scotland local authorities have different operating practices as to how service staff deal with service users who require invasive procedures to maintain their health and well-being. Indeed, within individual authorities there are different rules and regulations. Administration of such procedures is therefore a post code lottery. This obviously has major implications for the individual and also their parents/carers. Either the person is sent home when a procedure is required, or the parent/carer is requested to go to the service setting to administer the procedure themselves, or in some instances, the person is admitted to the nearest acute hospital. Many of these procedures are life saving and if they are not administered immediately when required the health of the individual may be further damaged.

There is clear evidence from research studies (Gibbs et al. 2008), reports (Mencap 2007) and the outcome of recent Fatal Accident Inquiries (FAIs) in Scotland, i.e. the Mauchland case (Dunbar 2003) and the Donnet case (Davidson 2007), that people with learning disabilities, and in particular those with profound and multiple learning disabilities, do not get equal access to health care provision when they are admitted to acute hospitals. Whilst none of these reports specifically note the need for the individuals concerned to have invasive procedures administered whilst in hospital, there is considerable anecdotal evidence that many nurses and other health care professionals in acute hospital settings do not have the training or experience

to meet the health needs of people with profound and multiple learning disabilities and complex health care needs.

Particular difficulties are encountered when a person with profound and multiple learning disabilities is admitted to a general hospital and into the care of nurses and medical staff unfamiliar with the variety of procedures including those that are invasive. A number of major concerns were raised at the Roderick Donnet enquiry, some of which reflected not only the need for improved staff training within the acute hospital setting but also within care homes where the delivery of medical care for people with a learning disability had failed. Lack of family involvement resulted in hospital nursing staff not accessing critical information while the confusion displayed by residential care staff as to who could or could not legally administer medication had a negative effect on the care Mr Donnet received (Patrick and Smith 2007). Additional research highlighted the lack of training acute hospital nursing staff receive in care for the patient with learning disabilities. Nursing staff reported their lack of training in this area as greatly affecting their confidence and competence in caring for people who have learning disabilities (Sowney and Barr 2006). Some family carers reported that when their relative was admitted to hospital, the family carers were heavily relied on to provide care. Many family carers continue to be the main carers even during hospital admissions with mothers stating that they were afraid to leave their child as they felt that hospital staff may unintentionally neglect their child through lack of understanding of his or her needs (Gibbs et al 2008). The delivery of all care, whether considered invasive or not, is dependent on appropriately trained carers from all sectors, including those who are family carers.

Across the range of social and health care settings noted in the foregoing, improving the delivery of invasive procedures has significant implications for the roles and skills of staff working directly with people with profound intellectual and multiple disabilities, as well as their managers and those who take policy decisions regarding the nature and quality of service provision. It is important to note that most family carers, notably parents, of people with profound and multiple learning disabilities carry out such procedures daily or at least on a regular basis. Training and support for them is highly important.

In the wider context of eliminating inequalities in health care for vulnerable groups, the Scottish Government (2008. p. 46) recommends action with respect to work force development. The report notes the importance of bringing together health *and* social care provision to ensure: "*Disadvantaged clients … receive the same quality of service as the rest of the population."* (p. 46). Moves to address the changes in delivery of care have been made. Shifts in community care have resulted in documents such as the *Community Care Outcomes Framework (Scottish Government 2008)* being drawn up to help partnerships understand their performance at a strategic level and to promote: improved health, social inclusion, well-being, independence and responsibility. This framework document identifies performance measures and targets that include: carer satisfaction with services; carers' support and ability to continue to care, as well as the shift in services to "home-based" care.

In order to ensure that these objectives are achieved with respect to people with profound intellectual and multiple disabilities and complex health needs the research project: *"Practice and Policy in the Administration of Invasive Procedures for People with PIMD",* supported by the Scottish Government, has been undertaken by *PAMIS' Invasive Procedures Working Group.* (2009-2010)

An important part of the project was the information collected at a consensus conference *Invasive Procedures: Breaking barriers and achieving control for people with profound & complex disabilities* was held on June 11th 2009 at the West Park Conference Centre, University of Dundee, Scotland (Garrard et al 2009). Delegates from a wide range of social, education and health care backgrounds, as well as family carers, attended. The recommendations that emerged from the conference have been integrated with survey findings to formulate the recommendations made in section 7 of this report.

## 1.1 Project components

The Invasive Procedures Research Project involves the following three components.

*1.1.1* A conference on invasive procedures in which, experts in this field reviewed available evidence and at which workshops to elicit the views of practitioners were held

*1.1.2* An extensive survey of policy and practice in Scotland with respect to delivering invasive procedures

*1.1.3* The work of an expert committee supported by a national reference group co-ordinating project activities and synthesising information.

## 1.2 Aims of the survey

The main aims of the survey questionnaire were to:

(i) determine, from the perspective of family and paid carers what constituted an invasive procedure

(ii) establish the extent to which barriers exist which precluded the delivery of such procedures in service settings and what these barriers were

(iii) identify ways in which barriers may be overcome, and:

(iv) more broadly, to describe examples of good practice in which barriers have been overcome

# 2 Method

Following on from the Invasive Procedures Conference held in June 2009 the second component of the project, involved an extensive survey of policy and practice in Scotland, with respect to delivering invasive procedures. Throughout the development and distribution of the survey questionnaire the expert committee and national reference group assisted and coordinated various aspects of the effort.

## 2.1 Organisation of the research programme

A project management group was established to provide advice and support to the research team. Members were drawn from diverse backgrounds having knowledge and experience of the issues that the project's remit addressed. Working group members included family carers, NHS staff, social work representatives, *PAMIS* staff and representation from NHS Education for Scotland (NES). A list of working group members can be found in Appendix 1

A reference group was set up consisting of: family carers, occupational therapists, clinical specialist dieticians, senior community dentists, clinical managers for continence, psychological services, consultant psychiatrists, learning disability liaison nurses, community nurses, specialist epilepsy and specialist PMLD nurses. Academics from relevant disciplines also assisted. Throughout the project members of the reference group gave valuable expert knowledge when needed. A list of reference group members can be found in Appendix 1.

## 2.2 Development of the questionnaire

Parallel questionnaires for family carers and professionals were developed. Following each question respondents were invited to comment further permitting both quantitative and qualitative analysis. The development of the questionnaire was challenging and piloted extensively. The information required necessitated a lengthy series of questions of some complexity. Family and professional questionnaires differed slightly. The same questions were asked but were worded differently to reflect the family experience and make the questions more meaningful to a family situation.

## 2.3 Draft questionnaire

A draft questionnaire was distributed in May 2009 to the members of the reference group who were asked to give feedback on the design and content with particular attention given to the relevance and value of the questions posed. Space was provided for any additional possible barriers or invasive procedures that it was judged should be included in the final version. Feedback helped identify any problem areas and was used to amend and clarify some questions.

## 2.4 Pilot Questionnaire

The finalised questionnaire was piloted in July 2009 to several family and paid carers. Based on the feedback received from the piloted questionnaire it was decided that an accompanying booklet, that would give further information and instructions on completing the survey, should be sent to the project sample. All additional procedures identified as invasive by pilot respondents and reference group members were incorporated into the final questionnaire. At this point the sample was identified and invited to complete the survey.

## 2.5 Sample

### *2.5.1 Geographical area involved*

The survey questionnaire was distributed to various areas across Scotland to allow a geographically balanced sample, which would also highlight practice from different local authorities and show where inconsistencies existed. The areas approached included: Aberdeen, Aberdeenshire, Angus, Dundee, Edinburgh, Fife, Glasgow, Highland, Orkney, Perth and Kinross, Shetland, South Lanarkshire and the Western Isles.

### *2.5.2 Identification of Care settings*

Suitable care settings were identified in areas where *PAMIS* is active. Initially it was anticipated that 200 care settings would be approached. In areas where *PAMIS* is not presently active, and where possible, professional contacts were asked to help identify facilities that care for people with learning disabilities and carry out procedures that could be viewed as invasive. There was difficulty in identifying relevant facilities in some areas. However, it was judged that rather than discount possible candidates, questionnaires should be posted to a number of facilities that may or may not carry out this level of care. If staff receiving the questionnaire judged that the survey was not relevant to their facility, their details were entered onto a withdrawal list. *PAMIS* area co-ordinators helped identify families within their areas who might be willing to participate. The type of care settings involved included:

a) Families caring at home
b) Adult Resource Centres
c) Community Services
d) Supported Accommodation
e) Education
f) Residential/Nursing Care Homes
g) Respite Units

These facilities were drawn from a wide range of service sectors, notably:

a) Local Authority
b) Voluntary sector
c) Education Private/ Local Authority
d) National Health Service
e) Private Nursing Care

Family carers who had a child with PMLD were approached and invited to complete the survey.

## 2.6 Distribution of the questionnaire

### *2.6.1 Families and care facilities*

In August 2009 the survey questionnaire was sent to care facilities and families with a cover letter explaining the project, why we were asking staff or families to fill out the questionnaire and how any information provided would be used. Respondents were assured that all data would be stored by the University of Dundee and would be subject to the Data Protection Act. It was also stressed that, although taking part in the study would be valuable, participation was entirely voluntary. The research team contact details were supplied so that anyone could 'phone or email the *PAMIS* office with any questions or to request assistance in completing any part of the questionnaire.

An instruction booklet explaining how to complete the document was also included and a freepost envelope was provided for the participant's convenience. After one month a follow-up letter was posted out to facilities and families who had not yet responded.

### *2.6.2 Objection to the questionnaire*

One local authority objected to their council day service facilities being contacted and asked that research permission paperwork was completed prior to further contact being made. A hold was placed on the facilities in question until the council requirements were satisfied.

### *2.6.3 Additional responses*

A number of professionals especially within the voluntary sector judged that colleagues in other geographical areas would be interested in completing the survey and so a number of additional late questionnaires were posted out.

### *2.6.4 Distribution of the questionnaire to educational facilities*

Directors of Education were approached both to explain the project remit and gain permission to contact relevant schools within their areas. However, there were some delays as additional paperwork had to be completed to satisfy some school authorities. One education authority judged that the

questionnaire was primarily health related and should therefore go through their NHS contact. This request was accommodated.

Twelve of the thirteen educational authorities contacted agreed to allow the research questionnaire to be distributed to their schools. As schools had just returned for the new academic year, distribution was delayed until September to allow staff time to settle in. Again four weeks later a follow up letter was posted out to schools that had not responded.

### *2.6.5 Withdrawal from the project*

There were specific reasons for withdrawing a possible participant or care facility from the project including:

a) Staff contacted us to say that the project was not relevant to their care setting

b) Professionals were not in a caring role within their job specification and did not feel they could give informed answers to the questions

c) A group of individuals had been sent separate questionnaires but subsequently answered one questionnaire as a team

d) Permission to contact carers was not given, e.g. one local authority did not grant permission to contact facilities in their area.

### *2.6.6 Response to the questionnaire*

Initial response was slow but picked up once possible participants received a follow up letter. Some staff contacted the research team to question the relevance of their work to the project. Where it was judged that a facility did not meet the project's criteria, such as not caring for anyone who received an invasive procedure, their details on the project database were assigned to the withdrawal column set up for such instances. Professionals who did not directly work with people in a care setting but who had been sent a questionnaire to complete were also withdrawn. Some families judged they needed help completing the survey and either contacted the research team to discuss further or were visited by the research assistant or the *PAMIS* Co-ordinator in their area.

### *2.6.7 Returned questionnaires*

The date for return of questionnaires was extended to the end of February 2010 to allow late survey requests to be returned. There were 534 questionnaires posted out with 168 categorised as withdrawals from the project. This resulted in a total of 366 questionnaires being distributed with 108 completed and returned. (30% return rate.) Seventy-eight professional carers and 30 family carers returned the survey questionnaire.

It was judged that a number of the remaining non-returned questionnaires were probably not relevant to the project but no contact was made by the facilities in question to confirm this. The return rate was almost certainly in excess of the stated 30%.

# 3 Data analyses

## 3.1 Quantitative data

Quantitative data from the questionnaire were entered into Statistical Package for the Social Sciences datasets. (Version 15.0)

## 3.2 Qualitative data

Questionnaire respondents were given space to provide free comment after each of the possible barrier questions. The comments were recorded and colour coded to identify words or synonyms that were used frequently. By using a word based technique to analyse the comments specific themes were identified (Ryan and Bernard 2010). The main themes included: Recognition of extra duties and remuneration; reference to training, need for extra staff, funding for training; legislation, including policies and procedures of care setting; job specifications highlighted; facilities that had some or most invasive procedures carried out by someone outwith their organisation; communication, relationships and partnership working.

## 3.3 Sectors

Specific comments were separated into the following groups: family carers; NHS; education; local authority; voluntary sector.

Identification of evidence of good practice was also required and responses to questions relating to practice that was positive and attempted to improve or solve issues was also recorded and separated into sectors. Geographical areas were highlighted too.

## 3.4 Missing data

There were a number of reasons for parts of the questionnaire not being completed:

a) The person assigned by the care setting to complete the survey judged that he or she was not qualified to answer specific parts of the survey, e.g. school nurse asked to complete the document but judged that policy questions concerning education were outwith her remit.

b) A question was not relevant to the respondent's situation, e.g. a family carer not having had any experience with unions.

c) Some facilities were in a transition phase i.e. policies on training involving non medical staff carrying out invasive procedures were undergoing change and so there was difficulty answering specific questions.

d) The facility did not have anyone who received certain invasive procedures therefore answers to questions about specific procedures may have been omitted.

# 4 Results

## 4.1 What is an invasive procedure?

Respondents were asked (question 1) which procedures in a list of 20 they considered to be invasive. Table 1 shows the percentage of all respondents who considered a procedure invasive, with the individual results for family members and paid staff indicated.

**Table 1:** Percentage of respondents judging a procedure to be **invasive**

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | 77.4 (82/106) | 76.7 (23/30) | 77.6 (59/76) |
| **2** Gastrostomy | 74.8 (80/107) | 73.3 (22/30) | 75.3 (58/77) |
| **3** Jejunostomy | 55.0 (55/100) | 32.0 (8/25) | 62.7 (47/75) |
| **4** Tracheal suctioning | 83.8 (88/105) | 75.0 (21/28) | 87.0 (67/77) |
| **5** Tracheal tube replacement | 85.6 (89/104) | 75.0 (21/28) | 89.5 (68/76) |
| **6** Postural drainage | 42.2 (43/102) | 57.1 (16/28) | 36.5 (27/74) |
| **7** Nebuliser | 19.2 (20/104) | 17.9 (5/28) | 19.7 (15/76) |
| **8** Oxygen | 25.0 (26/104) | 22.2 (6/27) | 26.0 (20/77) |
| **9** Short-term intermittent ventilation | 60.2 (62/103) | 63.0 (17/27) | 59.2 (45/76) |
| **10** Long-term intermittent ventilation | 66.0 (68/103) | 81.5 (22/27) | 60.5 (46/76) |
| **11** Manual bowel evacuation | 93.5 (100/107) | 86.7 (26/30) | 96.1 (74/77) |
| **12** Enema | 91.6 (98/107) | 86.7 (26/30) | 93.5 (72/77) |
| **13** Suppositories | 90.7 (97/107) | 86.2 (25/29) | 92.3 (72/78) |
| **14**Colostomy/Ileostomy care | 62.4 (63/101) | 57.7 (15/26) | 64.0 (48/75) |
| **15** Urethral catheters | 85.6 (89/104) | 89.3 (25/28) | 84.2 (64/76) |
| **16** Supra–pubic catheter | 79.4 (81/102) | 76.9 (20/26) | 80.3 (61/76) |
| **17** Pessaries | 85.7 (90/105) | 78.6 (22/28) | 88.3 (68/77) |
| **18** Injections | 76.6 (82/107) | 73.3 (22/30) | 77.9 (60/77) |
| **19** Applying skin creams | 21.9 (23/105) | 17.9 (5/28) | 23.4 (18/77) |
| **20** Oral/Nasal suctioning | 82.9 (87/105) | 82.1 (23/28) | 83.1 (64/77) |

There was a wide range of agreement with respect to whether any given procedure was regarded as invasive. For the whole sample this ranges from 93.6% for manual bowel evacuation to 21.9% for applying skin creams. When family respondents were compared with paid staff, there was no significant difference in their overall ratings of invasiveness (t=-44, d.f. 38, p>.05). Similarly the correlation between the judgements of the two groups was very high, $r$=.89, p<.01.

The only discrepancies between family members and staff were in the cases of jejunostomy where the former judged the procedure less invasive than staff (32.0% Vs 62.7%), and long-term intermittent ventilation about which the judgement went in the opposite direction (81.5% Vs 60.5%).

## 4.2 Possible barriers to procedures being carried out

Tables 2-10 show the percentage of respondents that judged an aspect of the situation presented a barrier to implementation of a procedure. It should be noted that NHS respondents gave answers relevant to their role, which showed that as fully qualified nursing/medical staff they saw few barriers to carrying out invasive procedures. This reduced the numbers of respondents overall who cited barriers to invasive procedures being carried out. However, respondents other than NHS staff, e.g. paid social care staff, with little or no nursing/medical training, were most likely to refer to barriers to invasive procedures being carried out.

For the purpose of the present analysis, we will look at the difference between the views of family carers and those of paid carers and the views of the respondents as a whole. We will consider each of these with respect to the nine possible barriers described in part one question 2 of the questionnaire. The second part of the questionnaire: *emergency medication for the community treatment of prolonged and serial epileptic seizures* will be subject to a separate report. Although the findings for all barrier questions fit well with respondent's comments, it is recognised that numbers were small and over reliance on percentage figures may be unreliable. However, we will highlight relevant comments that respondents made in response to questions regarding barriers, which will add depth and clarity to the findings.

### *4.2.1 Limited staff resources*

**Table 2:** Percentage agreement that **limited staff resources** present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **19.4** (14/72) | **14.3** (3/21) | **21.6** (11/51 |
| **2** Gastrostomy | **27.4** (20/73) | **42.9** (9/21) | **21.6** (11/52) |
| **3** Jejunostomy | **11.1** (8/72) | **4.8** (1/21) | **13.7** (7/51) |
| **4** Tracheal suctioning | **20.8** (15/72) | **4.8** (1/21) | **27.5** (14/51) |
| **5** Tracheal tube replacement | **20.8** (15/72) | **0** (0/9) | **29.4** (15/51) |
| **6** Postural drainage | **17.3** (13/75) | **14.3** (3/21) | **18.5** (10/54) |
| ***7*** Nebuliser | **12.3** (9/73) | **9.5** (2/21) | **13.5** (7/52) |
| **8** Oxygen | **15.1** (11/73) | **9.5** (2/21) | **17.3** (9/52) |
| **9** Short-term intermittent ventilation | **19.4** (14/72) | **14.3** (3/21) | **21.6** (11/51) |
| **10** Long-term intermittent ventilation | **15.3** (11/72) | **0** (0/9) | **21.6** (11/51) |
| **11** Manual bowel evacuation | **26.4** (19/72) | **9.5** (2/21) | **33.3** (17/51) |
| **12** Enema | **31.5** (23/73) | **23.8** (5/21) | **34.6** (18/52) |
| **13** Suppositories | **30.1** (22/73) | **23.8** (5/21) | **32.7** (17/52) |
| **14**Colostomy/Ileostomy care | **16.7** (12/72) | **9.5** (2/21) | **19.6** (10/51) |
| **15** Urethral catheters | **21.9** (16/73) | **4.8** (1/21) | **28.8** (15/52) |
| **16** Supra–pubic catheter | **16.7** (2/72) | **4.8** (1/21) | **21.6** (11/51) |
| **17** Pessaries | **22.2** (16/72) | **4.8** (1/21) | **29.4** (15/51) |
| **18** Injections | **23.6** (17/72) | **14.3** (3/21) | **27.5** (14/51) |
| **19** Applying skin creams | **28.9** (22/76) | **23.8** (5/21) | **30.9** (17/55) |
| **20** Oral/Nasal suctioning | **28.8** (21/73) | **33.3** (7/21) | **26.9** (14/52) |

As shown in table 2, limited staff resources were viewed by some respondents as a possible barrier for all procedures, ranging from administration of enemas (31.5%) to jejunostomy (11.1%). It was also evident that additional procedures that were seen as being most affected by staff resources were those involving suppositories (30.1%) and manual bowel evacuation (26.4%). Interestingly, applying skin cream, which was considered one of the least invasive procedures by respondents, could also be limited where there were staffing issues i.e. staff may not have time to apply creams. Respondents from some schools stressed the need for training to address the problem of limited staff resources. One school judged that an overview of insurance options to allow training would also help:

*Limited staff resources could be helped with more access to training, and better insurance options as insurance restrictions limit the number of staff we were able to train.*

Education

There were differences between family and paid staff responses with limited staff resources viewed, overall, as more of a problem for paid staff than for families. Families judged that staff limitations presented a significant barrier to procedures involving gastrostomies (42.9%) compared to 21.6% of paid carers. More than 30% of family respondents also saw oral nasal suctioning as a procedure limited by staffing availability. Both paid staff and families judged limited staff resources could be a barrier with procedures involving bowel care such as enemas 23.8% (families) and 34.6% (paid carers) and suppositories 23.8% (families) and 32.7% (paid carers). One family expressing anxiety around many issues. This included staffing resources in regard to qualified staff whom they judged were not skilled in carrying out tasks with their young son when hospitalised:

*As we were always with our son during hospital admissions we were providing ALL the care for him instead of nursing staff. This can be very hard at times- as it becomes an expectation of nursing/medical staff prior to and during his admission. I feel that staff lacks confidence with regard to dealing with children similar to our son who has complex and multiple medical needs. We feel that this is due to lack of training, knowledge and hands on "nursing". I would have various concerns and worries if neither my husband nor I could be with our son during a hospital admission.*

Parent Carer

There was also a marked disparity between paid carers and family views on tracheal tube replacement, with families intimating that there were no barriers compared to almost 30% of paid carers who considered tracheal tube replacement as being less likely to be carried out due to staffing issues. This may however have been due to few families actually dealing with tracheal tube replacement.

**Conclusion**
A proportion of respondents judged that the delivery of significant invasive procedures may be adversely affected by limitations to staff time. However, it was not only those procedures judged invasive that were so affected; thus limited staff resources and the lack of appropriately trained staff were viewed to affect all levels of care. Families identified areas of concern around acute care staff who are often unfamiliar with the care required for patients with learning disabilities and as a result heavily rely on family carers to continue to provide care during hospital admissions.

### *4.2.2 Limited staff competence*

**Table 3:** Percentage agreement that **staff competence** may present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **35.5** (27/76) | **13.6** (3/22) | **44.4** (24/54) |
| **2** Gastrostomy | **42.1** (32/76 | **50.0** (11/22) | **38.9** (21/54) |
| **3** Jejunostomy | **32.9** (25/76) | **4.5** (1/22) | **44.4** (24/54) |
| **4** Tracheal suctioning | **38.2** (29/76) | **4.5** (1/22) | **51.9** (28/54) |
| **5** Tracheal tube replacement | **43.4** (33/76) | **4.5** (1/22) | **59.3** (32/54) |
| **6** Postural drainage | **32.1** (25/78) | **18.2** (4/20) | **37.5** (21/56) |
| **7** Nebuliser | **18.4** (14/76) | **4.5** (1/22) | **24.1** (13/54) |
| **8** Oxygen | **30.3** (23/76) | **4.5** (1/22) | **40.7** (22/54) |
| **9** Short-term intermittent ventilation | **39.5** (30/76) | **4.5** (1/22) | **53.7** (29/54) |
| **10** Long-term intermittent ventilation | **39.5** (30/76) | **0** (0/8) | **55.6** (30/54) |
| **11** Manual bowel evacuation | **44.7** (34/76) | **9.1** (2/22) | **59.3** (32/54) |
| **12** Enema | **38.2** (29/76) | **22.7** (5/22) | **44.4** (24/54) |
| **13** Suppositories | **43.4** (23/76) | **31.8** (7/22) | **48.1** (26/54) |
| **14**Colostomy/Ileostomy care | **35.5** (27/76) | **9.1** (2/22) | **46.3** (25/54) |
| **15** Urethral catheters | **36.8** (28/76) | **9.1** (2/22) | **48.1** (26/54) |

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **16** Supra–pubic catheter | **31.6** (24/76) | **4.5** (1/22) | **42.6** (23/54) |
| **17** Pessaries | **34.2** (26/76) | **0** (0/8) | **38.1** (26/54) |
| **18** Injections | **35.5** (27/76) | **13.6** (3/22) | **44.4** (24/54) |
| **19** Applying skin creams | **20.3** (16/79) | **18.2** (4/22) | **21.1** (12/57) |
| 20 Oral/Nasal suctioning | 45.5 **(35/77)** | 36.4 **(8/22)** | **49.1** (27/55) |

Table 3 shows that overall, staff competence was considered a significant barrier to the delivery of invasive procedures relative to other possible barriers. Nebulisation (18.4%) and applying skin cream (20.3%) were viewed as least affected by staff competence. All other procedures were in comparison cited as being greatly affected by staff competence and ranged from oral/nasal suctioning (45.5%) to the administration of oxygen (30.3%).

Families judged strongly that staff competence was an issue in procedures involving gastrostomies (50.0%), oral/nasal suctioning (36.4%), suppositories (31.8%) and enemas (22.7%). As one parent commented:

*I get quite frustrated at times as I feel that I am the only person in my son's life that can administer an enema or perform manual evacuation.*

Parent Carer

Paid carers judged that staff competence was a major issue when carrying out most procedures. Applying skin cream (21.1%) and nebulisation (24.1%) were considered less likely to be a problem compared to all other procedures which ranged from tracheal tube replacement (59.3%) and manual bowel evacuation (59.3%) to postural drainage (37.5%). Local authority respondents judged that accessing training to allow staff to carry out procedures was important:

*Staff competence would improve if social care staff had access to training that would allow them to undertake invasive procedures. Our staff team want to be trained and want to carry out all the tasks but training for social care workers is not available.*

Local Authority Carer

The results suggest that procedures traditionally viewed as nursing tasks were considered procedures that non-medically qualified paid staff, from all care settings, have difficulty carrying out due to a lack of competence and training. Two family carers judged that this should be addressed:

*I believe that any staff with the appropriate training, skills and competency can undertake tasks which involve invasive procedures. Family carers already undertake such tasks with little or no training. I feel staff require generic training which is value-based, involves background knowledge and*

*understanding, develops appropriate skills and competencies and provides advice and guidance. This education and training needs to be ongoing and updated and should also be person specific. People need to be regarded as unique individuals-one model/method does not fit all. Any training and development of competencies and skills needs to be person-specific and person centred. For example, I know how to set up a gastrostomy feed for my daughter, administer medication via the gastrostomy and replace the tube; however, I do not know how to carry out these procedures for a friend's daughter who also has a gastrostomy tube. Family carers should be involved in this person-specific training.*

Parent Carer

*I believe the following is necessary:*

*Critical* *appropriate and ongoing training including competency skills*

*Essential* *family are integral part of training team*

*Produce* *Essential Life Plan (ONE PLAN) to cover all of cared for person's health/wellbeing/life/lifestyle.*

*Good relationships enable good communication, which supports trust/safety/openness.*

Parent Carer

*Staff competence would improve with better or more training. Problems do occur if legislation isn't relevant and policies were not updated to suit the needs of staff and service users.*

Community Shared House

**Conclusion**
A number of respondents judged that the delivery of significant invasive procedures may be adversely affected by staff competence with the majority of paid carers and family respondents commenting that training is the key issue that must be addressed. This is most clearly the case for local authority staff who often show willingness but found that they were restricted from accessing appropriate training. Some families also felt that as expert carers they should be involved in any person-specific training that is initiated.

### *4.2.3 Staff attitude*

**Table 4:** Percentage of respondents who judge **staff attitude** to be a barrier to implementation of a procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **35.7** (25/70) | **27.8** (5/18) | **38.5** (20/52) |

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **2** Gastrostomy | **35.7** (25/70) | **50.0** (9/18) | **30.8** (16/52) |
| **3** Jejunostomy | **45.7** (32/70) | **33.3** (6/18) | **50.0** (26/52) |
| **4** Tracheal suctioning | **40.0** (28/70) | **11.1** (2/8) | **50.0** (26/52) |
| **5** Tracheal tube replacement | **45.7** (32/70) | **11.1** (2/18) | **57.7** (30/52) |
| **6** Postural drainage | **25.0** (18/72) | **16.7** (3/18) | **27.8** (15/54) |
| **7** Nebuliser | **21.4** (15/70) | **16.7** (3/18) | **23.1** (12/52) |
| **8** Oxygen | **34.3** (24/70) | **22.2** (4/18) | **38.5** (20/52) |
| **9** Short-term intermittent ventilation | **44.1** (30/68) | **11.1** (2/18) | **56.0** (28/50) |
| **10** Long-term intermittent ventilation | **44.1** (30/68) | **16.7** (3/18) | **54.0** (27/50) |
| **11** Manual bowel evacuation | **47.8** (33/69) | **22.2** (4/18) | **56.9** (29/51) |
| **12** Enema | **47.8** (33/69) | **27.8** (5/18) | **54.9** (28/51) |
| **13** Suppositories | **46.4** (32/69) | **38.1** (7/18) | **49.0** (25/51) |
| **14**Colostomy/Ileostomy care | **36.2** (25/69) | **22.2** (4/18) | **41.2** (21/51) |
| **15** Urethral catheters | **41.4** (29/70) | **27.8** (5/18) | **46.2** (24/52) |
| **16** Supra–pubic catheter | **40.0** (28/70) | **22.2** (4/18) | **46.2** (24/52) |
| **17** Pessaries | **38.6** (27/70) | **11.1** (2/18) | **48.1** (25/52) |
| **18** Injections | **51.4** (36/70) | **27.8** (5/18) | **59.6** (31/52) |
| **19** Applying skin creams | **27.4** (20/73) | **38.9** (7/18) | **23.6** (13/55) |
| **20** Oral/Nasal suctioning | **40.0** (28/70) | **27.8** (5/18) | **44.2** (23/52) |

Again, as with competency, the percentage of respondents overall who judged that staff attitudes were a barrier to carrying out procedures was greatly increased compared to most other barrier questions (Table 4). Procedures described as being less affected were nebulisation (21.4%), postural drainage (25%) and the application of skin cream (27.4%). All other procedures ranged from injections (51.4%) to the delivery of oxygen (34.3%) were viewed as very much affected by staff attitude. There was a consistently high percentage of respondents overall who judged that most of the procedures listed were not ones that came under their job remit, whether qualified or not.

When comparing family and paid care staff responses,, there were marked differences of opinion. Families once again cited gastrostomies (50%) as being the most affected by staff attitudes, again in contrast to paid carers (30.8%), Families also considered applying skin creams (38.9%) and suppositories (38.1%) as being greatly affected by staff attitude. Most of the other procedures were seen as less of a problem than those cited by paid staff. It is interesting that staff attitude, from the family perspective, greatly affects the application of skin cream even though this is viewed as a relatively non-invasive procedure. One parent said that her son was denied access to day services if he required the application of skin cream for his eczema. As one parent commented:

*The day service staff will only put on sun cream and only if written consent is given. I feel that day centre staff should all be trained to carry out whatever procedure is necessary. It should be part of their job.*

Parent Carer

The percentage of paid staff who viewed procedures as affected by staff attitudes and conditions of employment or remit were, compared to families, much higher and ranged from injections 59.6% to nebulisation (23.1%). Eight procedures showed a percentage higher than 49%. Unsurprisingly, these procedures were tasks traditionally viewed as medical/nursing procedures.

Respondents' comments again stressed the need for training to alleviate this problem with significant reference made to the need for clear job specifications:

*Staff feel that levels of anxiety around carrying out invasive procedures will be reduced once training has been completed. Staff attitude toward some tasks will improve.*

Resource Centre

*Staff attitude improves if procedures were highlighted as part of the job specification. Staff need to be informed and understand what procedures they will be expected to carry out from the interview stage. Also, staff need to receive the proper training and support with any training including certification of competence.*

Housing Support

*It would be helpful if job descriptions were clear. Some teacher support staff have these duties included in their job description whereas others do not. There needs to be some consistency.*

Education

*In our facility staff do not have a problem with carrying out tasks once trained but management will not allow this.*

Resource Centre

*Staff attitude is good at our respite unit but although trained they were no longer allowed to carry out invasive procedures. The policies that stop trained staff carrying out invasive procedures need to be changed.*

Family Carer

**Conclusion**
Paid carers felt that they would benefit from training to alleviate anxiety surrounding carrying out many of the procedures described as invasive. Some paid carers stated that they were willing to be trained and carry out procedures but were not allowed access to such training by policies that already exist. Additionally, there were concerns around job specifications which show inconsistency especially within education settings. Families and staff would be more confident in the level of care provided if relevant training was accessible.

*4.2.4 Service agency policy/operating procedures*

**Table 5:** Percentage agreement that **service policy/operating procedures** may present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **24.1** (13/54) | **12.5** (2/16) | **28.9** (11/38) |
| **2** Gastrostomy | **33.3** (18/54) | **37.5** (6/16) | **31.6** (12/38) |
| **3** Jejunostomy | **28.3** (15/53) | **6.3** (1/16) | **37.8** (14/37) |
| **4** Tracheal suctioning | **32.1** (17/53) | **6.3** (1/16) | **43.2** (16/37) |
| **5** Tracheal tube replacement | **33.0** (18/53) | **12.5** (2/16) | **43.2** (16/37) |
| **6** Postural drainage | **21.8** (12/55) | **12.5** (2/16) | **25.6** (10/39) |
| ***7*** Nebuliser | **16.7** (9/54) | **0** (0/16) | **23.7** (9/38) |
| **8** Oxygen | **20.4** (11/54) | **0** (0/16) | **28.9** (11/38) |
| **9** Short-term intermittent ventilation | **28.3** (15/53) | **0** (0/16) | **40.5** (15/37) |
| **10** Long-term intermittent ventilation | **28.3** (15/53) | **0** (0/16) | **40.5** (15/37) |
| **11** Manual bowel evacuation | **35.8** (19/53) | **18.8** (3/16) | **43.2** (16/37) |
| **12** Enema | **33.3** (18/54) | **12.5** (2/16) | **42.1** (16/38) |
| **13** Suppositories | **35.2** (19/54) | **25.0** (4/16) | **39.5** (15/38) |
| **14**Colostomy/Ileostomy care | **26.4** (14/53) | **6.3** (1/16) | **35.1** (13/37) |
| **15** Urethral catheters | **33.3** (18/54) | **18.8** (3/16) | **39.5** (15/38) |

| | | | |
|---|---|---|---|
| **16** Supra–pubic catheter | **28.3** (15/53) | **12.5** (2/16) | **35.1** (13/37) |
| **17** Pessaries | **24.1** (13/54) | **0** (0/16) | **34.2** (13/38) |
| **18** Injections | **40.7** (22/54) | **18.8** (3/16) | **50.0** (19/38) |
| **19** Applying skin creams | **21.8** (12/55) | **20.0** (3/15) | **22.5** (9/40) |
| **20** Oral/Nasal suctioning | **32.2** (16/53) | **7.1** (1/14) | **38.5** (15/39) |

Overall, service agency policies/procedures were seen as being a possible barrier to some procedures being carried out by some respondents. (Table 5) In particular respondents judged that procedures, affected most were injections (40.7%), manual bowel evacuation (35.8%), and suppositories (35.2%). More than 30% of all respondents judged that agency policies also affected the administration of enemas and gastrostomy care. Nebulisation (16.7%), delivery of oxygen (20.4%) and postural drainage (21.8%) were viewed as least likely to be affected by service agency policies or procedures.

Family responses placed gastrostomies (37.5%), suppositories (25%) and the application of skin creams (20%) as procedures that were affected by service agency policies and procedures.

Paid staff considered almost all of the procedures were affected to some degree by agency policy and procedures. The degree to which policies formed a barrier again shows a link with procedures that were traditionally viewed as medical/nursing tasks.

Respondents' comments highlighted the need for changes in policy that would allow support /social care staff to carry out procedures that might traditionally be considered medical.

*Staff competence would improve if social care staff had access to training that would allow them to undertake invasive procedures. Our staff team want to be trained and want to carry out all the tasks but training for social care workers is not available.*

Local Authority Paid Carer

*Policy and guidelines need reviewed. Training staff and paying them appropriately to the level of responsibility may improve the situation.*

Education

*We work well with education staff in lots of instances however this depends very much on "goodwill". There is no standardised level of support. This makes it difficult to cover schools and limits the experience of the young person and his or her ability to experience the wider community. Some staff were very willing and see taking on these procedures as enhancing the young person's experience of school. Others see it as a nursing role and refuse to carry out procedures.*

Education

Families highlighted problems that existed including one parent who stated that applying skin cream was a problem due to service agency policies. Parents commented:

*All services stopped as no-one was able to care for my son's tracheotomy. The problems were around a policy, covering my son's situation, not being in place. Eventually training was given and staff were able to carry out the necessary procedures but this took nine months to resolve and my son was denied access to respite or the local play scheme during this time. Policies of service providers have meant that in the past I have had to be on call to carry out procedures. It would be more helpful if solutions to potential problems were in place prior to any crises or at least an idea of what to do so that delay in accessing services is minimised.*

Parent Carer

*My son's day centre policy will not allow eczema cream to be put on therefore when his eczema flairs and his skin breaks down he has to stay at home so that I can apply the cream.*

Parent Carer

*In my home carers that come in are not allowed to give my son medication only me. The home care agency policy does not allow agency staff to give medication. They were allowed to put medicine on a spoon but cannot actually give it. My son needs to be physically given the medication.*

Parent Carer

**Conclusion**
Both paid and family carers identified service agency policies and operating procedures as barriers to the delivery of a range of invasive procedures. The procedures most affected were ones which were most closely aligned with tasks that were traditionally viewed as nursing/medical tasks. Within Education some responses highlighted that there was no standardised level of support and that some support involving invasive procedures was often given on a voluntary basis. Relying on goodwill promotes inconsistencies.

### *4.2.5 Service agency commissioner's operating procedures*

**Table 6:** Percentage agreement that **service agency commissioners' operating procedures** may present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **14.9** (7/47) | **14.3** (2/14) | **15.2** (5/33) |
| **2** Gastrostomy | **19.1** (9/47) | **35.7** (5/14) | **12.1** (4/33) |

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **3** Jejunostomy | **14.9** (7/47) | **7.1** (1/14) | **18.2** (6/33) |
| **4** Tracheal suctioning | **19.6** (9/46) | **7.1** (1/14) | **25.0** (8/32) |
| **5** Tracheal tube replacement | **23.9** (11/46) | **14.3** (2/14) | **28.1** (9/32) |
| **6** Postural drainage | **8.2** (4/49) | **0** (0/16) | **11.4** (4/35) |
| ***7*** Nebuliser | **8.5** (4/47) | **7.1** (1/14) | **9.1** (3/33) |
| **8** Oxygen | **8.5** (4/47) | **0** (0/16) | **12.1** (4/33) |
| **9** Short-term intermittent ventilation | **15.2** (4/46) | **0** (0/16) | **21.9** (7/32) |
| **10** Long-term intermittent ventilation | **15.2** (7/46) | **0** (0/16) | **21.9** (7/32) |
| **11** Manual bowel evacuation | **26.1** (12/46) | **21.4** (3/14) | **28.1** (9/32) |
| **12** Enema | **23.4** (11/47) | **21.4** (3/14) | **24.2** (8/33) |
| **13** Suppositories | **27.7** (13/47) | **28.6** (4/14) | **27.3** (9/33) |
| **14**Colostomy/Ileostomy care | **13.0** (6/46) | **0** (0/14) | **18.8** (6/32) |
| **15** Urethral catheters | **25.5** (12/47) | **21.4** (3/14) | **27.3** (9/33) |
| **16** Supra–pubic catheter | **17.4** (8/46) | **7.1** (1/14) | **21.9** (7/32) |
| **17** Pessaries | **17.0** (8/47) | **0** (0/14) | **24.2** (8/33) |
| **18** Injections | **27.7** (13/47) | **14.3** (2/14) | **33.3** (11/33) |
| **19** Applying skin creams | **13.7** (7/51) | **20.0** (3/15) | **11.1** (4/36) |
| **20** Oral/Nasal suctioning | **21.3** (10/47) | **7.1** (1/14) | **27.3** (9/33) |

Overall, service commissioner's procedures were considered to create barriers principally with respect to injections (27.7%), suppositories (27.7%) and manual bowel evacuation (26.1%). Procedures considered least likely to be affected were nebulisation, (8.5%) the delivery of oxygen (8.5%) and postural drainage (8.2%) (Table 6).

Again, families were more likely to consider commissioner's procedures less of a problem than paid care staff. This is understandable given that commissioner's policies were less likely to be apparent to family members. However, there was a difference again in regard to gastrostomy procedures where 35.7% of families judged that gastrostomy care was affected by

commissioner's procedures compared to 12.1% of paid carers. Family response to the remaining procedures ranged from suppositories (28.6%) to supra-pubic catheters (7.1%) being viewed as least affected. A number of procedures were not viewed as being affected at all by commissioner's policies such as postural drainage, delivery of oxygen, pessaries and colostomy/illeostomy care. However, a number of parents did express their views on this:

*Funding issues mean that increasing services from Local Authority is not easily accessed. I am now an elderly parent needing extra help. My family were asked to step up their level of care instead. Our Local Authority agrees that I need extra services however there is no extra help coming through. Funding issues continue. If training was in place for non nursing staff then I would be O.K. with this. Carers that come in were not trained to do these procedures and therefore I have to do them. All carers should be trained as I might not be here in the future.*

Parent Carer

*Service providers and those that fund care need to change their thinking and attitude and this needs to show in their policies.*

Parent Carer

Paid staff judged that commissioner's procedures could be a barrier with injections (33.3%) and manual bowel evacuation (28.1%) considered tasks most likely to be affected. Applying skin cream (11.1%) and nebulising (9.1%) were viewed as least likely to be affected. Interestingly families disagreed in relation to the application of skin creams and judged that commissioner's procedures were likely to result in skin creams not being applied (20%).

A similar pattern emerged when the commissioner's operating procedures were compared with the agency policies and procedures and showed that procedures traditionally carried out by medical/nursing staff were more likely to be considered tasks outwith social care staff's job remit. Comments suggest that invasive procedures were still out-sourced to staff outwith the care setting. A need for policy review was stressed:

*Day services were in the middle of a best value review. Staffing issues will be part of what is being looked at. We have 8 day centre officers and 5 care assistants with 60 service users requiring care. Staff work in groups and if any service user required an invasive procedure a request to an appropriate person such as a nurse or doctor trained in the field to carry out the procedure would be made.*

Local Authority Day Services

*It would be helpful if all policies and procedures were reviewed as these need to reflect services being offered.*

Care Home

*The staff team feel that provided with the specific training relevant to the procedure they would be happy to carry out the procedures as it would provide consistency of care to our client group. However, all were aware that we have to work to the National Care Standards and Organisational Policies and Procedures – so changes have to be backed up by relevant Government Legislation.*

*Staff attitude would improve if training, backed up by legislation that permits carers to undertake such procedures, was in place along with organisational update of policies and procedures. It would make a difference if policies and procedures were less restrictive. Carers should be supported by change in legislation. National Care Standards need to be reviewed.*

Respite Unit

**Conclusion**
Commissioners' operating procedures were restrictive in some instances. Policies that prevent care staff from actually giving a person medication result in multiple agency participation where a person centred approach and relevant training might allow a single agency to carry out the task. The results parallel the outcome of service agency barriers where staff show willingness but policies do not allow non medical staff to carry out even simple tasks such as administering prescribed medication.

### *4.2.6 Consent issues*

**Table 7:** Percentage agreement that **consent issues** may present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **13.3** (6/45) | **7.7** (1/13) | **15.6** (5/32) |
| **2** Gastrostomy | **26.7** (12/45) | **30.8** (4/13) | **25.0** (8/32) |
| **3** Jejunostomy | **20.0** (9/45) | **15.4** (2/13) | **21.9** (7/32) |
| **4** Tracheal suctioning | **15.9** (7/44) | **0** (0/13) | **22.6** (7/31) |
| **5** Tracheal tube replacement | **18.2** (8/44) | **7.7** (1/13) | **22.6** (7/31) |
| **6** Postural drainage | **8.5** (4/47) | **7.7** (1/13) | **8.8** (3/34) |
| ***7*** Nebuliser | **11.1** (5/45) | **7.7** (1/13) | **12.5** (4/32) |
| **8** Oxygen | **11.1** (5/45) | **7.7** (1/13) | **12.5** (4/32) |
| **9** Short-term intermittent ventilation | **13.6** (6/44) | **0** (0/13) | **19.4** (6/31) |

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **10** Long-term intermittent ventilation | **13.6** (6/44) | **0** (0/13) | **19.4** (6/31) |
| **11** Manual bowel evacuation | **27.3** (12/44) | **38.5** (5/13) | **22.6** (7/31) |
| **12** Enema | **22.2** (10/45) | **15.4** (2/13) | **25.0** (8/32) |
| **13** Suppositories | **26.7** (12/45) | **30.8** (4/13) | **25.0** (8/32) |
| **14**Colostomy/Ileostomy care | **13.6** (6/44) | **0** (0/13) | **19.4** (6/31) |
| **15** Urethral catheters | **22.2** (10/45) | **15.4** (2/13) | **25.0** (8/32) |
| **16** Supra–pubic catheter | **15.9** (7/44) | **7.7** (1/13) | **19.4** (6/31) |
| **17** Pessaries | **15.6** (7/45) | **0** (0/13) | **21.9** (7/32) |
| **18** Injections | **20.0** (9/45) | **0** (0/13) | **28.1** (9/32) |
| **19** Applying skin creams | **20.8** (10/48) | **15.4** (2/13) | **22.9** (8/35) |
| **20** Oral/Nasal suctioning | **17.8** (8/45) | **7.7** (1/13) | **21.9** (7/32) |

Overall, consent issues were considered by respondents to be more problematic in relation to procedures that were again traditionally viewed as nursing tasks. (Table 7) These ranged from manual bowel evacuation (27.3%) to postural drainage (8.5%). However, it is perplexing that issues around consent were considered as great for the application of skin cream (20.8%) as for injections (20.0%) and tracheal tube replacement (18.2%).

Families viewed consent as a problem in relation to manual bowel evacuation (38.5%) and gastrostomies (30.8%). Consent was viewed as less important in relation to postural drainage (7.7%), nebulisation, (7.7%) and the delivery of oxygen (7.7%). A number of families also judged there were no problems in relation to short-term ventilation, long-term ventilation, tracheal suctioning and colostomy/illeostomy care. However, this could again be due to families not having personal experience of these procedures as opposed to viewing them as non-problematic. Family's consent was not an issue if there was confidence in the carer's ability to carrying out the procedure:

*Staff competence would improve if staff were given the proper training, by the appropriate people and also given the chance to carry out the procedure regularly. Policies need to be in place to provide training to those who require it and want it and the necessary insurance. If I am absolutely sure of their competence and if staff have a good attitude I have no problems with consent.*

Parent Carer

*The more training there is the fewer problems, around attitude toward emergency procedures, exist. Policies to provide better trained staff who have experience and knowledge of these procedures were required. Flexibility of policies is necessary to accommodate the different needs of individuals. This would help me feel more confident.*

Parent Carer

Paid staff were overall more likely to see problems in carrying out a procedure due to consent issues related to consent of the person with PMLD. Procedures that families had identified as having no consent issues were in contrast viewed differently by paid staff such as: tracheal suctioning (22.6%), short and long term ventilation (19.4%), and colostomy/illeostomy care (19.4%). Some paid carers responded by referring to legislation which allows procedures to be carried out where consent was an issue.

*We have The Adults with Incapacity Act manual which takes us through steps required for any consent issue.*

Local Authority Council

*A number of parents have welfare guardianship*

Local Authority Day Centre

*Having wider usage of the Welfare Guardian option is one way of addressing consent issues. A social worker has been appointed to deal with Adults with Incapacity issues – specifically to set up guardianship orders and Powers of Attorney.*

NHS

**Conclusion**
There appeared to be underlying anxieties experienced by family carers who do not have trust established or confidence in staff abilities which spills into attitude toward paid carers in all areas of care. Overall, staff that are trained and competent would reduce family carers' levels of anxiety and increase family trust and confidence that their relative is receiving a high standard of care at all times. If families felt they could trust carers they would be less likely to raise questions around consent.

*4.2.7 Care plan issues*

**Table 8:** Percentage agreement that the **care plan** may present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **17.0** (8/47) | **9.1** (1/11) | **19.4** (7/36) |
| **2** Gastrostomy | **17.0** (8/47) | **27.3** (3/11) | **13.9** (5/36) |

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **3** Jejunostomy | **17.0** (8/47) | **18.2** (2/11) | **16.7** (6/36) |
| **4** Tracheal suctioning | **19.6** (9/46) | **0** (0/11) | **25.7** (9/35) |
| **5** Tracheal tube replacement | **23.9** (11/46) | **9.1** (1/11) | **28.6** (10/35) |
| **6** Postural drainage | **8.2** (4/49) | **9.1** (1/11) | **7.9** (3/38) |
| ***7*** Nebuliser | **4.3** (2/47) | **0** (0/11) | **5.6** (2/36) |
| **8** Oxygen | **12.8** (6/47) | **0** (0/11) | **16.7** (6/36) |
| **9** Short-term intermittent ventilation | **17.4** (8/46) | **0** (0/11) | **22.9** (8/35) |
| **10** Long-term intermittent ventilation | **15.2** (7/46) | **0** (0/11) | **20.0** (7/35) |
| **11** Manual bowel evacuation | **23.9** (11/46) | **18.2** (2/11) | **25.7** (9/35) |
| **12** Enema | **21.3** (10/47) | **9.1** (1/11) | **25.0** (9/36) |
| **13** Suppositories | **23.4** (11/47) | **18.2** (2/11) | **25.0** (9/36) |
| **14**Colostomy/Ileostomy care | **17.4** (8/46) | **18.2** (2/11) | **17.1** (6/35) |
| **15** Urethral catheters | **25.5** (12/47) | **27.3** (3/11) | **25.0** (9/36) |
| **16** Supra–pubic catheter | **17.4** (8/46) | **9.1** (1/11) | **20.0** (7/35) |
| **17** Pessaries | **17.0** (8/47) | **0** (0/11) | **22.2** (8/36) |
| **18** Injections | **21.3** (10/47) | **9.0** (1/11) | **25.0** (9/36) |
| **19** Applying skin creams | **14.0** (7/50) | **27.3** (3/11) | **10.3** (4/39) |
| **20** Oral/Nasal suctioning | **21.3** (10/47) | **0** (0/11) | **27.8** (10/36) |

Overall, respondents identified care plans as presenting possible barriers in carrying out procedures ranging from urethral catheters (25.5%), tracheal tube replacement (23.9%), and manual bowel evacuation (23.9%). Procedures that were less affected were delivery of oxygen (12.8%) postural drainage (8.2%) and nebulising (4.3%) (Table 8).

The number of procedures cited by family respondents as not being carried out due to care plans was lower than other possible barriers. However, there were still some issues. Gastostomies, application of skin cream and urethral catheters were each viewed by 27.3% of families as procedures that could be limited due to care plan stipulations. Procedures less affected were injections

(9.0%) and both postural drainage and tracheal tube replacement (both 9.1%). Again a number of procedures were viewed as not being affected by the care plan at all. However, some procedures which were rarely carried out as part of a relative's daily care may have influenced this result. The more common tasks such as gastrostomies, catheters and postural drainage were highlighted by families:

*Changing policies, training staff and providing positive information to all service providers would make a positive difference to the care given. In regard to the care plan, more involvement, sharing information and discussion with the Welfare Guardian by service providers before, during and after the care plan has been processed is necessary.*

Parent Carer

Paid staff carers were more inclined to see problems with care plans which ranged from tracheal tube replacement (28.6%); oral/nasal suctioning (27.8%) and manual bowel evacuation (25.7%) at the higher end of the scale, to those less likely to be affected such as applying skin creams (10.3%), postural drainage (7.9%) and nebulisers (5.6%). Again differences of opinion existed in regard to application of skin cream with over 27.3% of families compared to only 10.3% of paid carers viewing the care plan as possibly being a barrier to the task being performed:

*Any care plan needs to have full clear guidelines and background on medical issues with reasons for introduction of a procedure. It should be clearly stated if a procedure requires medical professionals or can be carried out by support staff. Organisation policy needs to be in line with government policies.*

Housing Support

*In regard to the care plan, more involvement, sharing information and discussion with the Welfare Guardian by service providers before, during and after the care plan has been processed is necessary.*

Parent Carer

**Conclusion**

Families considered that information was not always shared regarding care plans and that there was a lack of family involvement in drawing up care plan documents. Paid carers stressed the need for clear guidelines and background information on medical issues with reasons for introduction of a procedure stated. Care plans are in place to make sure care is appropriately carried out and to clarify exactly what should and should not be done in certain situations. As the care plan objective is to make sure that it is customised for the individual's needs and is in place to ensure care is carried out it is surprising that the care plan should be cited as a barrier to procedures. However, this would be the case where the plan mirrored the policies and procedures of the service agency and or the agencies' commissioning procedures and in particular the policies around divisions between social care and medical/nursing care. It is also possible that updating of plans is not robust enough.

### *4.2.8 Union interventions*

**Table 9:** Percentage agreement that **union intervention** may present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **18.9** (7/37) | **14.3** (1/7) | **20.0** (6/30) |
| **2** Gastrostomy | **24.3** (9/37) | **28.6** (2/7) | **23.3** (7/30) |
| **3** Jejunostomy | **16.2** (6/37) | **14.3** (1/7) | **16.7** (5/30) |
| **4** Tracheal suctioning | **16.7** (6/36) | **0** (0/7) | **20.7** (6/29) |
| **5** Tracheal tube replacement | **16.7** (6/36) | **0** (0/7) | **20.7** (6/29) |
| **6** Postural drainage | **10.3** (4/39) | **0** (0/7) | **12.5** (4/32) |
| ***7*** Nebuliser | **8.1** (3/37) | **0** (0/7) | **10.0** (3/30) |
| **8** Oxygen | **13.5** (5/37) | **0** (0/7) | **16.7** (5/30) |
| **9** Short-term intermittent ventilation | **13.9** (5/36) | **0** (0/7) | **17.2** (5/29) |
| **10** Long-term intermittent ventilation | **13.9** (5/36) | **0** (0/7) | **17.2** (5/29) |
| **11** Manual bowel evacuation | **22.2** (8/36) | **0** (0/7) | **27.6** (8/29) |
| **12** Enema | **24.3** (9/37) | **0** (0/7) | **30.0** (9/30) |
| **13** Suppositories | **24.3** (9/37) | **0** (0/7) | **30.0** (9/30) |
| **14**Colostomy/Ileostomy care | **16.7** (6/36) | **14.3** (1/7) | **17.2** (5/29) |
| **15** Urethral catheters | **21.6** (8/37) | **14.3** (1/7) | **23.3** (7/30) |
| **16** Supra–pubic catheter | **11.1** (4/36) | **0** (0/7) | **13.8** (4/29) |
| **17** Pessaries | **21.6** (8/37) | **0** (0/7) | **26.7** (8/30) |
| **18** Injections | **21.6** (8/37) | **0** (0/7) | **26.7** (8/30) |
| **19** Applying skin creams | **12.5** (5/40) | **14.3** (1/7) | **12.1** (4/33) |
| **20** Oral/Nasal suctioning | **24.3** (9/37) | **0** (0/7) | **30.0** (9/30) |

Union directives were understandably more likely to be cited as an issue by paid carers (Table 9). The main procedures precluded by union directives, within the overall group, were again in relation to procedures that were traditionally classed as nursing/medical procedures such as provision of enemas (24.3%), suppositories (24.3%), oral/nasal suctioning (24.3%) and manual bowel evacuation (22.2%). Those on the lower end of the scale were application of skin cream (12.5%), postural drainage (10.3%) and nebulising 8.1%.

Families again did not judge that there were any problems with a number of these procedures with respect to union intervention. This is perhaps more to do with not having contact or knowledge of union policy and not being involved in carrying out some of the procedures. The one procedure that families did cite as being of concern regarding union policy involved gastrostomies (28.6%), which were, unusually, relatively close to the paid carers' view (23.3%).

*Training was given to classroom staff for gastrostomy feeding/care but then the issue of payment for these extra responsibilities arose. Despite training most staff have opted not to carry out procedures. Union issues mean that staff want more money to carry out gastrostomy feeding and care.*

Parent Carer

Paid carers identified union policy as affecting the carrying out of procedures such as delivery of enemas (30%), suppositories (30%) and nasogastric tube feeding (20%). Procedures considered less likely to warrant union intervention were postural drainage (12.5%), applying skin cream (12.1%) and nebulising (10%). Education staff and nursing staff within school settings described difficulties with job descriptions and union involvement:

*Union difficulties exist as specific bands e.g. Band 3 nursing assistants job description does not allow them to give medication. Updating job descriptions might help. Updated training also avoids health and safety issues. Unions need to recognise the need for job descriptions to be changed to include giving rescue medication and some basic medication, i.e. Paracetamol. (Band 3) Changes here would also help with health and safety issues.*

Education

*Unison feels that education staff need to be trained and appropriately paid for many of these procedures to be carried out and if staff were to have this level of responsibility.*

Education

*Union issues exist as we have had various instances where staff have volunteered for training then withdrawn after union advisor intervention. There were ongoing issues as this is an education department remit. The union often state that staff members were not insured to carry out procedures. It would be helpful if policies stated that some invasive procedures were categorised as personal care.*

Education

*Union issues can be avoided if clearer guidelines and more accurate job remits were in place. We brought in union representatives to help answer questions and resolve issues.*

Education

*The unions would clearly use many of these procedures to broker a pay rise for their staff and this has been the case with gastrostomy and rescue medication which will now be carried out.*

Local Authority Day Centre

**Conclusion**

Respondents considered that union negotiations must continue and solutions found especially with respect to remuneration. Within education settings one family stated that despite training most staff have opted not to carry out gastrostomy care procedures. The reason given was union intervention as payment for extra responsibility was not in place. One care facility also stated that negotiations with unions regarding remuneration had recently taken place to allow gastrostomy care and rescue medication to be carried out by staff.

Some respondents judged that it would be of benefit if the category identified as personal care was reformed to include some of the less complex invasive procedures that were presently only carried out by medically trained professionals.

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### *4.2.9 Health and safety issues*

**Table 10:** Percentage agreement that **health and safety issues** may present a possible barrier to implementation of the procedure

| Invasive procedures | All respondents | Family respondents | Staff respondents |
|---|---|---|---|
| **1** Nasogastric tube | **11.9** (5/42) | **12.5** (1/8) | **11.8** (4/34) |
| **2** Gastrostomy | **16.7** (7/42) | **37.5** (3/8) | **11.8** (4/34) |
| **3** Jejunostomy | **11.9** (5/42) | **12.5** (1/8) | **11.8** (4/34) |
| **4** Tracheal suctioning | **14.6** (6/41) | **0** (0/8) | **18.2** (6/33) |
| **5** Tracheal tube replacement | **14.6** (6/41) | **0** (0/8) | **18.2** (6/33) |
| **6** Postural drainage | **9.1** (4/44) | **0** (0/8) | **11.1** (4/36) |
| ***7*** Nebuliser | **2.4** (1/42) | **0** (0/8) | **2.9** (1/34) |
| **8** Oxygen | **9.5** (4/42) | **0** (0/8) | **11.8** (4/32) |

| | | | |
|---|---|---|---|
| **9** Short-term intermittent ventilation | **17.1** (7/41) | **0** (0/8) | **21.2** (7/33) |
| **10** Long-term intermittent ventilation | **17.1** (7/41) | **0** (0/8) | **21.2** (7/33) |
| **11** Manual bowel evacuation | **22.0** (9/41) | **0** (0/8) | **27.3** (9/33) |
| **12** Enema | **16.7** (7/42) | **0** (0/8) | **20.6** (7/32) |
| **13** Suppositories | **19.0** (8/42) | **0** (0/8) | **23.5** (8/34) |
| **14**Colostomy/Ileostomy care | **12.2** (5/41) | **12.5** (1/8) | **12.1** (4/33) |
| **15** Urethral catheters | **26.2** (11/42) | **25.0** (2/8) | **26.5** (9/34) |
| **16** Supra–pubic catheter | **24.4** (8/41) | **25.0** (2/8) | **24.2** (8/33) |
| **17** Pessaries | **16.7** (7/42) | **0** (0/8) | **20.6** (7/34) |
| **18** Injections | **19.0** (8/42) | **12.5** (1/8) | **20.6** (7/34) |
| **19** Applying skin creams | **13.3** (6/45) | **25.0** (2/8) | **10.8** (4/37) |
| **20** Oral/Nasal suctioning | **23.8** (10/42) | **12.5** (1/8) | **26.5** (9/34) |

Again health and safety concerns were cited as being a barrier overall in procedures that were traditionally performed by nursing/medical staff. Urethral catheterisation (26.2%), supra-pubic catheterisation (24.4%), oral nasal suctioning (23.8%), and undertaking injections and delivery of suppositories (both 19%). Least affected by health and safety issues were procedures involving nasal gastric tube feeding and jejunostomies (11.9%), provision of oxygen (9.5%), postural drainage (9.1%) and nebulising (2.4%).

Families again dismissed a number of procedures as not an issue in contrast to paid carers. The highest scoring procedure was gastrostomy with 37.5% of family respondents judging that there were issues related to this procedure regarding health and safety that could stop gastrostomy procedures from being carried out. There was a marked difference from paid carers where only 11.8% judged that there were health and safety issues in delivering a gastrostomy.

One mother commented on what she had put in place to avoid health and safety issues for her daughter:

*Production of an Essential Life Plan for my daughter has been critical to her health and safety. It is also a meaningful resource for all caregivers. Her Essential Life Plan is updated and disseminated by family, is always current/relevant and accessible to all at the same time with same information.*

Parent Carer

*Health and safety issues would be improved if there was more flexibility and less fear of litigation. Staff need to put the person's needs before their own.*

Parent Carer

*Many care agencies do not allow their staff to perform certain procedures due to fear of being sued if something goes wrong. This results in protocol procedures not being carried out. In regard to health and safety common sense would help.*

Parent Carer

**Conclusion**

Concerns regarding health and safety issues existed especially with respect to invasive procedures that are traditionally considered nursing/medical tasks. Although families were less concerned with health and safety overall they did consider gastrostomy care as being one procedure that was problematic. Families were three times more likely to judge gastrostomy care as a health and safety issue compared to paid carers. This disparity is evident in data recorded for practically all possible barriers where gastrostomy care is being considered.

# 5 Evidence of good practice

It should be noted that many of the suggestions put forward by survey respondents, as changes that could make a positive difference and reduce barriers to the delivery of invasive procedures, had already been carried out to a certain degree by some care facilities in an attempt to address problems. In addition, the consensus workshops (Garrard et al 2009) identified models of good practice that were summarised in the earlier report. The information provided from these two sources has allowed identification of good practice that could be shared across all areas of Scotland and help reduce the anomalies that exist. The information is displayed and separated for sector group.

## 5.1 Families and training

Family carers throughout the survey urged the importance of their knowledge of their relative to care planning and the delivery of invasive procedures. Their role in training staff was noted in relation to several barriers, not least the issue of staff competence. Several initiatives were identified nationally that drew on the experience of family carers:

5.1.1 One Lanarkshire family carried out training for school carers on gastrostomy care and feeding. School staff were then able to provide the necessary care for their child during the school day.

5.1.2 A Fife family gave training on postural drainage and oral suctioning which allowed staff, coming into their home, to provide the necessary care their daughter required. It also allowed them as family carers to leave their daughter knowing that staff were well able to perform these tasks when necessary.

5.1.3 A South Lanarkshire mother provided training and effective ileostomy/stoma care instructions with a chart that recorded: checking/draining and changing. This mother also produced an Essential Life Plan for her daughter, which has been critical to her health and safety and a meaningful resource to all caregivers. (Updated and disseminated by family-always current/relevant and accessible to all at the same time with same information.) She also provided equipment, materials, instructions, risk assessments and contracts which have been endorsed by the family GP and relevant professionals. The methodology of the Essential Life Plan is also available on the Joint Improvement Team Website which means that other families and professionals can benefit from this example of good practice (Allan 2008).

## 5.2 NHS training

Lack of training and in particular availability of training for non-nursing staff within community settings was repeatedly cited as an issue by both family and paid carers. Evidence of integrated working within policies and procedures with examples of sharing information and provision of training and steps to

improve experiences for both people with PMLD and their carers is welcome. A number of different initiatives have been cited as evidence of good practice within NHS Quality Improvement Scotland's (QIS) online publication, Supporting Information for Tackling Indifference. The evidence cited within the QIS publication gives a broad range of good practice that does not always specifically mention invasive procedures but would be beneficial in the delivery of invasive procedures. (NHS Quality Improvement Scotland 2009) Some examples from survey data and NHS QIS are included below and under NHS policies and procedures (5.1.3):

5.2.1 Care workers in Aberdeen undergo theory/practical training and must have all competencies signed by a trained nurse prior to working unsupervised in a child's own home. Any care plans that are involved have specific carer responsibilities laid out. The plan explains what the care worker's responsibilities are, i.e. "care worker can care for child on oxygen but parent/trained nurse to start/stop oxygen therapy." Sharing information and providing training to non medical staff has been beneficial as has the clarity provided in robust care plans.

5.2.2 NHS Grampian gathers information from patients, carers and staff involved in the learning disabled person's care and reviews the experience from all aspects. The experience of everyone involved in an event such as appointment, admission, x-ray, medical procedure etc. is explored. The idea is to pull themes together and look at how to enhance consultations and improve patient care. For further information contact: june.brown@nhs.net

5.2.3 Conference attendees drew attention to NHS Ayrshire and Arran's use of social stories to support the learning disabled person's understanding of procedures and link nurses have been appointed to work with general practitioners to improve primary care and the needs of learning disabled patients (Garrard et al 2009).

5.2.4 NHS Borders has piloted a GP Communication Tool which allows medical staff to use pictures to help communicate with patients who do not have language skills and or limited understanding. Use of the tool allows some patients who have learning disabilities understand what is happening or going to happen during a procedure and avoids some issues regarding consent (NHS Quality Improvement Scotland May 2009).

5.2.5 NHS Fife and Fife Social Services jointly provide respite care for people with PMLD at a residential unit. Nursing staff from the joint respite care team also provide care in the community to at least one family. This evidence of partnership working was identified at the project conference (Garrard et al 2009).

5.2.6 In Lanarkshire resource packs and going to hospital leaflets - acute liaison resource packs are widely available and contain contact details for both the acute liaison practitioner and the adult learning disability services contacts. Having access to information on the liaison practitioner and adult learning disability services allows carers and professionals to access further information that may assist when questions arise concerning invasive

procedures or any issues surrounding caring for a patient who has learning disabilities. For further information contact:

Jean.Howieson@lanarkshire.scot.nhs.uk

## 5.3 NHS policies and procedures

5.3.1 Some instances of invasive procedures not being carried out due to lack of communication between different agencies can be avoided if an integrated approach to working is adopted. The Roll-out of care programme approach model - an integrated and embedded care programme approach process, with a lack of barriers across services, reinforcing good joint working in relation to the undertaking of assessments and sharing of information between health and social work services. Documentation has been adapted into accessible formats, such as easy read care plans and information packs for service users and carers (NHS Quality Improvement Scotland 2009).

5.3.2 Cervical screening package, 'Healthy Women's Project' - the healthy women's project resource pack was created in Lothian by a project team working with women who have learning disabilities and their carers. (Healthy Woman's Project 2010) Of particular relevance a range of resources was developed, including patient information leaflets, a carers' guide and guidelines for good practice in primary care.

Dysphagia guidance - joint multidisciplinary guidance is accessible to NHS Grampian staff and regularly reviewed (NHS Quality Improvement Scotland 2009).

## 5.4 Education training

Survey data shows that training issues are a concern in all facilities where care is provided including schools. School support staff would benefit from training that would allow them to develop skills required to carry out certain procedures. Evidence of educational training that improves the situation within school facilities and under education policies and procedures is documented:

5.4.1 In Glasgow, nurses based in schools supporting students with complex needs, Specialist Nurse Trainers use competency based workbooks which have already been successfully used to train volunteers from education and respite units. School support staff are able use the workbooks to gain competency in caring tasks involving, e.g. gastrostomies, nasal gastric tubes and tracheal suctioning. When necessary the Specialist Nurse Trainers go out to mainstream schools to provide training. For further information contact (angela.hall2@nhs.net)

5.4.2 Nursery nurses in Fife have recently been given training in some skills such as tracheal suctioning, gastrostomy and oral suctioning. Training is provided by the new post education facilitator from the Community Children's Nursing Team. The staff feel supported and have gained confidence knowing

that they can consult with the education facilitator should there be any questions or issues.

## 5.5 Education policies and procedures

Policy changes are necessary to allow staff within schools to carry out some procedures that are considered invasive. Policy changes that allow support staff to carry out invasive procedures, e.g. delivery of emergency medication, also allows children to gain access to community activities as support staff are not dependent on school nursing staff to carry out emergency procedures. Survey respondents considered job specifications to lack clarity causing misunderstandings in relation to employee expectations in regard to invasive procedures:

5.5.1 An Aberdeen school has modified job descriptions to accommodate staff duties and a Glasgow school has updated their job descriptions, which may avoid problems in relation to employee attitude.

5.5.2 Staff at a school in South Lanarkshire reported that most pupils have been changed over to Buccal Midazolam which is less intrusive and easier to administer. This allows support staff to administer emergency medication and also allows most children to go on out-of-school trips.

## 5.6 Local authority

Survey respondents intimated that lack of access to training, lack of integrated working and issues around union directives were areas that created barriers to provision of care. The following examples show where agencies working together have had positive effects on the care provided. They also show that negotiation with unions followed by policy and procedural changes resulted in a positive approach to care (5.1.7).

5.6.1 Glasgow has introduced the Specialist Health Support Policy document which outlines the training and learning framework, which has been put in place to support the introduction and operation of the policy. Training has two themes: General Policy Awareness and Specific Health Topic/Service User Training. Training will be tailored around specific needs to service users and focus on the individual support required as part of their care plan. Service managers/deputes will receive training and will then be responsible for cascading this to their team in their Community Health and Care Partnerships.

## 5.7 Local authority policies and procedures

5.7.1 Glasgow Learning Disability Partnership and Community Health and Care Partnership have introduced the Specialist Health Support document which will mean that social care staff will receive training allowing some procedures to be carried out by non – medical staff. This shift in policy is the result of negotiations with Unions.

5.7.2 Angus has initiated a "*Team Around the Child*" approach. The 'Team around the child' refers to a care co-ordination role where there is multi-agency involvement with a child with complex needs.

## 5.8 Voluntary sector training

Voluntary sector staff who completed the survey echoed the need to access relevant training. Conference attendees highlighted training agreements with NHS Tayside and survey respondents drew attention to training that can be accessed through a mixture of other voluntary agencies and specialists within NHS services. Additionally, issues concerned with organisational procedures and policies and importantly the need for adequate insurance coverage for staff, who carry out invasive procedures, was highlighted. Some steps toward addressing issues around liability coverage are documented within voluntary sector policies and procedures (5.1.9):

5.8.1 Conference attendees highlighted that Capability Scotland has a training agreement in place with NHS Tayside which states that staff members who require specific training to support all individual service users will be trained by NHS Tayside Staff to gain competency in delivering care with refresher training provided as required. Non-medical staff are therefore able to carry out tasks that would traditionally be performed by nurses. Care staff that are trained allows the level of care to improve and improve the lives of those they care for (Garrard et al 2009).

5.8.2 An East Renfrewshire voluntary facility has accessed training from a number of different groups such as Centaur, Quarriers and the local Community Learning Disability Team, Speech and Language Therapists and accessed Communication Techniques training. By working together and sharing knowledge carers are able to improve their skills and the lives of service users.

5.8.3 Personal Communication Passports have been developed by *PAMIS* and other organisations have used similar documents to assist in communication for those who have no speech. *PAMIS* passports also, where relevant, document important information regarding various invasive procedures e.g. gastrostomy care. Where relevant, family Welfare Guardianship is acknowledged with contact information provided, which is helpful when paid carers need to consult the person's family around consent etc.

5.8.4 *PAMIS* has also provided training and support for family and paid carers on a wide range of health topics, including invasive procedures (*PAMIS* 2010).

## 5.9 Voluntary sector policies and procedures

5.9.1 One voluntary facility in Dundee consulted with insurance providers in regard to employee and public liability insurance. This has resulted in insurers agreeing that carers can carry out invasive procedures, that a family member can undertake, as long as the appropriate training is in place.

5.9.2 In Aberdeenshire, facility staff have insurance cover to allow them to administer Buccal/Nasal Midazolam to their client group. This will allow clients to be given emergency medication quickly and more efficiently by care staff.

### 5.10 Scottish Government

The consensus is that services should work together to allow a more integrated service to emerge. The Joint Improvement Team (JIT) is part of the Partnership Improvement and Outcomes Division within the Scottish Government's Health Directorates. Comments from the survey referred to the Talking Points Personal Outcomes Approach JIT initiative. Although this example is not directly related to invasive procedures it does show that through different approaches the person who has learning disabilities can be communicated with at a better level and gives practitioners insight into the person's reality. With better understanding of the learning disabled person's reality and challenges in life a more considerate approach in everyday care and particular care needs can be made.

The Talking Points: Personal Outcomes Approach is very much a practical resource that allows practitioners to improve listening and observation skills and through practical exercises allows them to gain a better understanding of a learning disabled person's reality. (Joint Improvement Team 2010)

*"A significant minority of people who use health and social care services have communication support needs. They may have a physical disability which prevents them from using natural speech or a learning disability or a condition that leaves them temporarily in need of support to communicate. This resource is designed to support practitioners to have conversations with people despite these challenges. It is designed for use by multi-disciplinary teams, building on practitioners' existing knowledge and skills to develop capacity and confidence levels." (Walker et al 2010)*

Conclusion

While all the examples of good practice noted above are to be welcomed, we found no evidence that they had been systematically evaluated. Except in a few cases (e.g. negotiations with a union), their specific impact on removing the barriers described in this report has yet to be established. It is also clear that the examples are highly localised and do not reflect any national strategic guidance. There would be value in reviewing the initiatives to establish how they could be integrated in a complementary fashion and their impact evaluated.

# 6 Conclusion

We have emphasised the identification of barriers to the delivery of invasive procedures by paid staff and family members. In a sense we have drawn attention to the glass half-full, as in only a few cases did the majority of staff respondents identify a given barrier to a particular procedure. There were such examples, however. Over 50% of staff respondents judged lack of staff competence to be a barrier to the delivery of tracheal suctioning, tracheal tube replacement, short- and long-term ventilation and manual evacuation. Staff attitudes were judged by half or over half of staff members to act as a barrier to all these procedures, in addition to which delivery of enemas and giving injections were also cited. Nevertheless, all other barriers explored were cited by some staff members as obstacles to the delivery of all procedures.

A corollary of these findings is that in Scotland, all procedures are being delivered unobstructed by the barriers considered in a wide range of settings, i.e. it *is* possible to make such provision in educational and day service facilities. Nevertheless, where barriers preclude delivery, the impact on the individual with profound and multiple learning disabilities and on their family is profound, as reported in the written comments of family carers. Anxiety and lack of confidence in staff, exclusion from services, demands on family members to undertake the procedures themselves are the consequence. In general, family members cited fewer barriers than did staff. In part this may be lack of awareness of wider issues in service delivery, e.g. the role of commissioners, but as pointed out by some of them, *family members deliver all of these invasive procedures in their own homes year in and year out*.

The survey did not address the complex issue of how the various barriers may interact and reinforce each other. For example, if operating procedures preclude delivery of an invasive procedure, this will make training of staff irrelevant and hence staff competence and attitudes will inevitably act as barriers to delivery. In drawing on the findings to suggest how all barriers may be removed and ensure that every child and family receives the health care to which they are entitled, the barriers need to be considered in a strategic framework in which initiatives at a number of levels are integrated and feed into each other. Though lack of competence on the part of staff emerged as a principal concern, the situation can only be improved if at all levels – national policy, commissioning requirements, operating procedures and union involvement support the role of staff and ensure training is effective and can be put into action.

The role of the family in such a strategy is critical, both in terms of their intimate knowledge of their relative and in the contribution they can make to the work of professional staff. They should occupy a key role within any strategic framework aimed at improving the delivery of invasive procedures to children and adults in Scotland.

We have therefore framed the recommendations arising from this survey in terms of the various levels that need to be addressed to ensure that all barriers are removed from the delivery of all invasive procedures.

## 6.1 Policy and procedures

Before steps to change policies and procedures can be initiated questions related to legislation relevant to the delivery of invasive procedures must be reviewed. Restrictions in the delivery of invasive procedures placed on paid carers need to be addressed and the legal status of their actions clarified. Clear procedures in an explicit legal framework that includes a definitive statement on the role of welfare guardianship in decision making, relevant to invasive procedures, should also be made. Once legislation and its impact on policy has been reviewed and the implications of legislation for policy have been ascertained, policies and procedures at interagency level can be tackled.

### Recommendation 1.1 Legal issues

It is recommended that:

Legislation relevant to the delivery of invasive procedures and its impact on policy should be reviewed and a clear statement prepared on the implications of legislation for policy in the delivery of invasive procedures.

Aim: To ensure that the legal context in which invasive procedures are delivered is clear and procedures are undertaken in an explicit legal framework and with a clear statement on the role of welfare guardianship in decision making relevant to the delivery of invasive procedures

Action: The Scottish Government should commission a review of the legal provisions affecting the delivery of invasive procedures and issue guidance on the legal context for delivering such procedures.

Validation: There will be an annual audit made by all organisations that carry out invasive procedures to ensure that all procedures are delivered within the agreed legal framework

Outcome: All invasive procedures will be delivered within a legal framework including clarity regarding the role of the welfare guardianship.

Proposed Time Scale: March 2011

Procedures most affected by service agency policy and operating procedures appear to be ones which were most closely aligned with tasks traditionally viewed as nursing and/or medical tasks. Respondents' comments highlighted that local authority policies that prevent social care staff from accessing training and education and associated staff job remits should be reviewed. The outcome of such an exercise should be to prevent the possible exclusion from services reported by some families. Commissioner's operating procedures were also seen as restrictive in some instances. Policies that prevent care staff from giving a person medication result in multiple agency participation, where a person centred approach and relevant training might allow a single agency to carry out the procedure. Views on commissioners' operating procedures parallel the outcome of service agency barriers where staff show willingness, but policies do not allow non-medical staff to carry out even simple tasks such as the administration of prescribed medication.

Survey respondents expressed concerns regarding job specifications which showed inconsistency especially within education settings. Union intervention was cited as presenting barriers to some levels of care, particularly with respect to remuneration. Negotiations with union officials must continue and solutions found in relation to constraints on the delivery of invasive procedures. Removal of such constraints will in turn influence staff attitudes and ultimately the effectiveness of delivery of such procedures. This in turn will give families more confidence in the level of care their relative receives, while relevant training will increase staff confidence.

Nationally, a review of policies and procedures at both interagency level which in turn impact on individual services and facilities is called for. Through such collaboration people with profound and multiple learning disabilities will be guaranteed the health care to which they are entitled, and the burden of care for families will be mitigated.

**Recommendation 1.2 Integrated policies and procedures**

It is recommended that:

A national review be undertaken to develop clear guidelines on policies and procedures regarding the responsibility of service providers to ensure that all people with profound and multiple learning disabilities receive health care interventions to meet their needs in whatever service facility they access.

Aim: All people with PMLD will be treated equitably with respect to meeting health care needs in the service settings to which they are entitled.

Action: The Scottish Government should initiate the review in collaboration with national representative health, education and social care bodies, and with the relevant trades unions.

Validation: A review will be undertaken by the Scottish Government one year after formulation of the national guidelines.

Outcome: Consistent and equitable practice with respect to meeting the health care needs of people with PMLD will be met and monitored throughout Scotland as a result of nationally agreed guidelines.

Proposed
Time Scale: By June 2011

The implementation of national guidelines should be reviewed and implemented at local level. This will ensure that the local agencies responsible for the delivery of care have clearly stated operational practices that are delivered consistently across all geographical areas of Scotland. Comprehensive health care at any service setting to which a person with profound and multiple learning disabilities is entitled will be delivered and exclusions or withdrawals due to non-availability of procedures will no longer occur.

**Recommendation 1.3 Policies and procedures of individual facilities**

It is recommended that:

In the light of Recommendations 1.1 and 1.2 the implementation of the national guidelines should be reviewed and implemented at local level.

Aim: All providers of services to people with profound and multiple learning disabilities will provide safe and effective delivery of invasive procedures to them by utilising the nationally agreed invasive procedures guidelines.

Action: Community Health Partnerships will set up working groups with representatives from all relevant agencies responsible for delivering services to people with profound and multiple learning disabilities and family carers, to take implement the national invasive procedures guidelines.

Validation: The performance management and inspection protocols for the Social Work Inspection Agency (SWIA) and Her Majesty's Inspectorate of Education (HMIe) or their successor will incorporate review of the implementation of the national procedures agreed.

Outcome: At local level agencies responsible for the delivery of invasive procedures will have clearly stated operational practices consistent with national guidelines enabling staff to deliver safe and effective intervention to people with profound and multiple learning disabilities. This will ensure that will all receive comprehensive health care in any service setting to which they

are entitled and exclusions or withdrawals because of non-availability of procedures will be eliminated.

Proposed
Time Scale: Working groups set up by May 2011, policies implemented by March 2012

## 6.2 Workforce Development

*Community Care Outcomes Framework (Scottish Government 2008)* provides a framework for performance measures and targets that include: carer satisfaction with services as well as carers' support and their ability to continue to care as there is a move to home-based care. The experience of paid and unpaid carers who completed the invasive procedures survey questionnaire helps shed light on where changes need to be made and indeed where successful practice has already begun to address areas where barriers to care exist. One solution proposed was reforming categories identified as personal care to include some of the less complex invasive procedures that are presently only carried out by medically trained professionals. Issues related to health and safety need to be addressed and relevant policies or legislation reviewed to allow paid carers to access relevant training which would allow them to carry out procedures without fear of litigation.

**Recommendation 2.1 Identification of workforce that deliver invasive procedures**

It is recommended that:

In the light of national guidelines explicit specifications will be agreed by management, unions and the skills sector regarding job roles and expectations.

Aims: To develop in partnership a workforce that is fit, safe and effective in the delivery of invasive procedures and thus ensures people with profound and multiple learning disabilities can access the services to which they are entitled.

Action: In partnership with professional and regulatory bodies the skills sector and partnership forums within health, education, social care and the voluntary sector will review the skills required to carry out invasive procedures and identify the workforce that will be delivering these procedures.

Validation: An audit of personal development reviews and inclusion of subsequent workforce changes within the NHS Knowledge and Skills Framework (KSF) and any equivalent social care development tool should be made to ensure that development

needs in relation to invasive procedure delivery are highlighted.

Outcome: Clarity regarding job specifications and responsibilities will ensure that professional barriers to the delivery of invasive procedures in a care and service settings are removed.

Proposed
Time Scale: April 2011 Job descriptions released March 2012

A proportion of respondents judged that the delivery of significant invasive procedures may be adversely affected by limitations of staff time. However, it is not only those procedures judged invasive that were so affected; thus limited staff resources and the lack of appropriately trained staff can affect all levels of care. The majority of paid carers and family respondents commented on staff competence and judged training was the key issue that must be addressed. This was most clearly the case for local authority staff who often showed willingness but found that they were restricted from accessing appropriate training.

**Recommendation 2.2 Education of staff**

It is recommended that:

All relevant staff supporting people with profound and multiple learning disabilities, including non-nursing staff, should be trained in relevant invasive procedures.

Aim: To have all staff working with people with profound and multiple learning disabilities receive the education and skills development that will enable them to carry out allocated invasive procedure tasks safely and competently.

Action: NHS Education for Scotland and SSSC, in collaboration with Sector Skills Councils (Skills for health and Skills for Care and Development) should identify core skills required to carry out invasive procedures and map these to the NHS Knowledge and Skills Frame work and any equivalent social care development tool. Educational resources to ensure that all staff possess the skills to carry out allocated invasive procedure tasks, should be developed. Analyses of family carer educational/ training needs should be fed into the process. Managers should ensure that all staff, involved in the delivery of invasive procedures, have learning and development needs, in relation to invasive procedures, identified within their personal development reviews and for new staff within their induction. This information needs to be fed into an initial learning needs analysis. NHS Education for Scotland and SSSC will ensure that all appropriate education is available within new graduate induction e.g. NMAHP flying start NHS, social work and education and within the NMAHP

effective practitioner work stream. NES should ensure involvement from medical and dental professions to support the delivery of invasive procedures. The Scottish Clinical Skills Network will be used to support learning and skills development through the use of clinical skills simulation.

Validation: Review of learning needs via NHS Knowledge and Skills Framework for health and social care's equivalent care development tool should be carried out. Audit of personal development plans for all other sectors.

Outcome: All staff will be competent to deliver relevant invasive procedures in the context of their service.

Proposed
Time Scale: From April 2011

Family carers carry out invasive procedures within the home on a daily basis and yet most have had little of no access to any formal training. Training programmes involving invasive procedures that are offered to paid carers should be accessible to family carers if needed. Some family carers also judged that as expert carers they should be involved in any person-specific training that is initiated. Family carers as experts should be considered partners in care and where relevant be involved in person specific training opportunities.

**Recommendation 2.3 Education and family carers**

It is recommended that:

Any training programmes involving invasive procedures available to paid care staff should be offered to family carers who wish to attend. Family carers should be regarded as partners in care and as such given the same opportunities as paid care staff to access relevant training opportunities and where relevant be involved in the delivery of person specific training.

Aim: To ensure that family carers have up-to-date information and where relevant support the education of others.

Action: NHS Education for Scotland and Scottish Social Services Council (SSSC), *PAMIS* and other relevant supportive services.

Validation: NHS Education for Scotland in partnership with SSSC will develop educational resources that are accessible to all including family carers. (See: Rec. 2.2)

Outcome: Families and care staff will have a common knowledge base enabling more consistent treatment across services and family

homes. Information exchange will be more effective and where relevant, family carer expertise will be utilised.

Proposed
Time Scale: Commencing December 2010

Importantly, one group of carers, lacking necessary training are escorts and drivers who accompany people with profound and multiple learning disabilities to and from their various facilities. Staff supporting them during transportation should receive training in emergency procedures.

**Recommendation 2.4 Training of transportation staff**

It is recommended that:

Staff supporting people with profound and multiple learning disabilities during transportation to and from facilities e.g. escorts, should receive regular and relevant training with respect to meeting health care needs in an emergency e.g. the safe delivery of rescue medication.

Aims: To ensure that staff involved in accompanying people with profound and multiple learning disabilities are able to meet health care needs in an emergency. All care staff responsible for transportation will be fully competent and their knowledge base will remain updated.

Action: Management should carry out an assessment of health and safety policies and ensure that all transportation staff accompanying people with PMLD access training recommended (See: Rec. 2.2) to ensure escort and other relevant transportation staff are fully trained and able to meet health care needs when required.

Validation: The fitness for purpose of the training of escort and transportation staff should be included in all inspection initiatives by the relevant audit and inspection agencies.

Outcome: All staff accompanying people to and from facilities will be fully trained in meeting the needs of the person with PMLD in an emergency.

Proposed
Time Scale: March 2011

Acute care settings are not exempt. Lack of staff resources, issues around competence and the unsaid expectation that family carers will remain with their relative and continue to care while he/she is hospitalised were reported.

General hospitals should ensure that policies are in place to accommodate patients with profound and multiple learning disabilities who require invasive

procedures to be carried out. Reliance on family carers should not be depended on to supplement staffing issues around competency and or resources.

**Recommendation 2.5 Education within acute health care**

It is recommended that:

Operating polices should be established in general hospitals to ensure that when a person requiring invasive procedures is admitted, nursing and other medical staff are fully briefed and trained or have access to a suitably trained person in the delivery of required procedures. Family carers' experience and expertise should be acknowledged and utilised to enhance care of the person with profound and multiple learning disabilities.

Aim: To ensure that the health needs of the person with profound and multiple learning disabilities are fully met while in hospital and family members have confidence that they can leave their relative in safe hands.

Action: NHS Boards should review the training and resource requirement with respect to delivering invasive procedures in acute hospital services used by people with profound and multiple learning disabilities and consider this in the context of clinical governance and patient quality assurance.

Validation: Health Boards should review annually, families' and paid carers' satisfaction with the delivery of invasive procedures while their relative or resident is an inpatient.

Outcome: Health care involving invasive procedures will be delivered safely by nursing and other medical staff in NHS facilities. Family expertise will be acknowledged and used to improve person centred care. Family carers will be confident that the procedures can be delivered safely in their absence.

Proposed
Time Scale: March 2011

With regard to issues related to consent within the general hospital setting, staff who are trained and competent will reduce family carers' levels of anxiety and increase family trust and confidence that their relative is receiving a high standard of care at all times. If families feel they can trust nursing and medical staff they are less likely to raise questions regarding consent. Involving families and working in partnership would reduce the need to call on legislation such as the *Adults with Incapacity Scotland Act* and other legal responses.

**Recommendation 2.6 Education of acute care staff concerning consent**

It is recommended that:

Training on the issues of capacity and consent to treatment, including the powers of welfare guardians, should be provided to nursing and other medical staff in general hospitals.

Aim: All relevant staff in general hospitals will understand the legal context in which the determination of capacity is made and powers of a welfare guardian in decision making.

Action: The training sections of NHS Boards will coordinate and deliver relevant training to hospital staff involved in caring for patients with profound and multiple learning disabilities, with respect to legislation on capacity and consent with special reference to the *Adults with Incapacity (Scotland) Act 2000* and the powers in decision making of family welfare guardians. Undergraduate programme co-ordinators will ensure that relevant legislation on issues to do with capacity and consent are incorporated into all undergraduate medical and nursing degree programmes.

Validation: The adequacy of such training should be reviewed by Community Health Partnerships.

Outcome: The issue of consent will cease to act as a barrier to the delivery of invasive procedures as general hospital care teams will be able to act in accordance with the legislation. The role of a welfare guardian will be clear to members of the team where issues related to capacity and consent are raised.

Proposed
Time Scale: October 2011

## 6.3 Care Plans

Paid carers highlighted the need for clear guidelines and background information on medical issues. Care plans must be robust, and importantly, state explicitly who should and should not deliver invasive procedures. Family experience highlights the importance of family welfare guardianship being acknowledged by service providers. Where relevant, the identity of the welfare guardian and their role in decision making for the person with profound and multiple learning disabilities should be clearly documented within the plan. Information should be shared at all stages of plan development and with all relevant people involved.

**Recommendation 3.1 Identification of staff responsible for delivery of invasive procedures within care plan document**

It is recommended that:

Individual care plans should state explicitly the roles and responsibilities of those delivering invasive procedures, and state the identity and role of a welfare guardian where relevant.

Aim: To have robust and transparent care plans in place in which staff responsibilities and those of welfare guardians is identified and the information is readily accessible.

Action: The manager of the service will ensure that care plans reflect this recommendation and are brought to the attention of all relevant staff and also family carers.

Validation: Community Health Partnerships and Social work Departments will review policies and procedures to ensure that care plans comply.

Outcome: Care plans will be robust, coordinated and easily accessible with clear policies, procedures and guidelines resulting in improved standards of care. Welfare Guardian's powers will be recognised and will influence the care plan.

Proposed
Time Scale: October 2011

Families considered that information was not always shared regarding care plans and that there was a lack of involvement in drawing up care plan documents. The importance of family involvement and partnership working is critical in all areas of care including development of care plans. Family involvement will enhance care and promote a more person centred approach to care overall. Family carers want to be involved where possible as the more knowledge of the cared-for person that is available, the better the care the person will receive.

**Recommendation 3.2 Care plans and family involvement**

It is recommended that:

The development of care plans for people requiring invasive procedures should always involve partnership working with family carers in planning and reviewing the actions required to meet the individual's health care needs.

Aim: To ensure that care plans are fully informed by the views and experiences of family carers leading to enhanced delivery of invasive procedures.

Action: Care facility managers will involve family carers in the development of care plans, their review and updating.

Validation: Annual reviews of care plans and assessment of family involvement will determine whether family carers' views have been taken account of.

Outcome: The delivery of invasive procedures will be enhanced in their effectiveness through the input of family members who will be less anxious in the knowledge that staff is fully competent to undertake the procedures.

Proposed
Time Scale: October 2011

Survey respondents acknowledged concerns regarding changes in medication/procedures and or the speed at which notification to carers is given regarding changes once a person with profound and multiple learning disabilities was discharged from hospital. General hospital discharge policies must ensure that changes to medication/procedures are documented and disseminated quickly to all relevant carers to ensure a high level of care continues post discharge.

**Recommendation 3.3 Acute care discharge protocol**

It is recommended that:

Protocols are developed to ensure that on discharge from a hospital family or paid carers are made aware pre-discharge in writing of any necessary changes in health care procedures including medication. The pre-discharge information should include contact details for relevant health care advice.

Aim: To ensure continuity of care through family and paid carers being fully briefed on post-discharge medical needs.

Action: Health Boards should review relevant issues concerning clinical governance and quality assurance for patients to ensure that relevant protocols guarantee transfer of information to family and paid carers. Discharge policies in relation to changes to medication and or procedures should be reviewed to ensure that when an individual with profound and multiple learning disabilities moves from one setting to another, continuity of good practice in the delivery of invasive procedures is ensured through the development of effective protocols. Care plans should be updated with a process of disseminating information

quickly to all relevant carers involved in the community including family carers, day services, schools etc. established. Steps to allow access to expert advice post discharge should be made.

Validation: NHS staff responsible for clinical governance and quality assurance should review implementation of discharge protocols annually.

Outcome: Confusion regarding changes in procedures and or medication, post-hospitalisation, will be removed and promote continuity of care. Continued access to expert medical opinion and information will be available after the person with profound and multiple learning disabilities has been released to community care.

Proposed
Time Scale: October 2011

We noted above that to achieve the aim of the effective delivery of invasive procedures to all people with profound and multiple learning disabilities in Scotland, initiatives will have to be integrated at all levels. We conclude by suggesting that following discussion with the Scottish Government and relevant parties, the above recommendations are integrated into a strategic plan with implementation overseen by the Scottish Government or a relevant delegated body.

The principal limitation to the present study was the difficulty in achieving the desired sample size. Though this was in excess of 30%, the number of responses precluded more detailed analysis by sectors, e.g. local authority, NHS. However, the picture that has emerged is internally highly consistent, and indeed consistent with the concerns indicated in the consensus workshops (Garrard et al 2009) and in the wider field. Further analysis is merited with respect to combinations of barriers in relation to the most invasive procedures.

# 7 Glossary

**Application of skin creams:** application of topical substances or manipulation of devices to promote skin integrity and minimize skin breakdown

**Colostomy/Illeostomy:** colostomy/Illeostomy is an opening that is made in the colon or illeostomy with surgery. After the opening is made, the colon is brought to the surface of the abdomen to allow stools to leave the body

**Enema:** insertion of a tube into the rectum to infuse fluid into the bowel and encourage a bowel movement.

**Gastrostomy:** a surgical opening into the stomach. This opening may be used for feeding usually via a feeding tube called a gastrostomy tube

**Injection:** is an infusion method of putting fluid into the body, usually with a hollow needle and a syringe which is pierced through the skin to a sufficient depth for the material to be forced into the body

**Jejunostomy:** a tube into the small intestine is called a jejunostomy and is used for feeding usually via a feeding tube called a jejunostomy tube

**Long-term intermittent ventilation:** is required when a person requires long-term assistance to breath. Long-term ventilation assists with the exchange of oxygen and carbon dioxide in the alveoli (the tiny air sacs) in the lungs.

**Manual bowel evacuation:** is the digital removal of faeces from the rectum, in certain patients who are unable to empty the bowel independently.

**Nasogastric tube:** a tube that is passed through the nose and down through the nasopharynx and esophagus into the stomach

**Nebuliser:** a nebuliser is a device used to administer medication to people in the form of a mist inhaled into the lungs

**Oral/Nasal suctioning:** removal of secretions from the oral/nasal cavity to keep a person's airway clear**.**

**Oxygen:** delivery of oxygen often through a face mask

**Pessaries:** a medicated vaginal suppository

**Postural drainage:** drainage of mucus from specific areas of the lungs by placing the body in a specific position

**Short-term intermittent ventilation:** is required when a person required short-term assistance to breath. The ventilation assists with the exchange of oxygen and carbon dioxide in the alveoli (the tiny air sacs) in the lungs

**Suppository:** a drug delivery system that is inserted into the rectum (rectal suppository), vagina (vaginal suppository) or urethra (urethral suppository), where it dissolves

**Supra pubic catheter**: a tube that's inserted through the abdomen to connect directly into the bladder to drain urine

**Tracheal Suctioning:** tracheostomy suctioning removes thick mucus and secretions from the trachea and lower airway that a person is not able to clear by coughing. Suctioning is conducted through a tracheal tube

**Tracheal tube replacement:** replacement of tracheal tube in the trachea to maintain the airway

**Urethral catheter:** a narrow flexible tube passed into the bladder through the urethra to drain urine

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# Appendix 1

## Invasive Procedures Working Group Members

| | |
|---|---|
| Ms Isobel Allan | Family Carer, South Lanarkshire |
| Dr Michael Brown | Nurse Consultant & Lecturer, NHS Lothian |
| Ms Alison Corp, | Learning Disability Epilepsy Nurse Specialist, NHS Glasgow |
| Ms Vivienne Davidson | Rep. ADSW Learning Disability Committee |
| Ms Brenda Garrard | Research Assistant, *PAMIS* University of Dundee |
| Prof. James Hogg | W.T.R.U. University of Dundee |
| Ms Loretto Lambe | *PAMIS* Director, University of Dundee |
| Ms Jenny Millar | NHS Education for Scotland |
| Ms Maureen Philip | *PAMIS* Co-ordinator Tayside |
| Ms Cindy Wallis | Rep. ADSW Learning Disability Committee |
| Jenny Whinnett | Family Carer and *PAMIS* Co-ordinator Grampian |

## Reference Group members (43)

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|---|---|---|
| Sarah Whiteley | Clinical Manager for Continence | Glasgow |
| Dr Mary Ray | Consultant Paediatrician (Alexander Hosp) | Glasgow |
| Dr Philip Davies | Consultant in Paediatric Respiratory Medicine | Glasgow (Yorkhill) |
| Liz Platt | *PAMIS* Co-ordinator | Glasgow |
| Leigh Bennett | SALT | Glasgow |
| | | |
| Jonathan Kallow | Senior Community Dentist | Fife |
| Sandra Morrison | Learning Disability Liaison Nurse | Fife |
| Jessie Roberts | *PAMIS* Co-ordinator | Fife |
| Jane Russell | Parent Carer | Fife |
| Dr Martin Campbell | School of Psychology St Andrews University | Fife |
| Louise Falconer | Staff Nurse Paediatrics | Fife |
| Joyce McDonald | Senior OT | Fife |
| Mary McFarlane | Service Manager Aberlour | Fife |
| | | |
| Lesley Burnett | Dundee Adult Learning Disability Team Leader | Tayside |
| Maureen Philip | *PAMIS* Co-ordinator | Tayside |
| Lorraine Blair | Senior Specialist Continence Nurse | Tayside |
| Joyce Burns | Senior Occupational Therapist | Tayside |
| Gillian Stephen | Specialist PMLD Nurse | Tayside |
| Kirsty Hamilton | Clinical Specialist Dietitian | Tayside |
| Hannah Young | Research assistant *PAMIS* | Dundee |
| Carina Mitchell | Parent Carer/Advocating together | Dundee |
| Rose Anne Main | Service Manager Capability Scotland | Dundee |
| Lynne McHugh | Service Manager Cornerstone | Dundee |
| Susan McLaren | Assistant Co-ordinator *PAMIS* | Tayside |
| Doug Fairweather | Resource Centre Manager | Angus |
| Caroline Ritchie | Psychiatrist | Dundee |
| Marie France | Parent Carer | Perth |
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| Gillian Thain | Specialist Respiratory Physiotherapist (Adults) | Grampian |
| Jenny Whinnett | *PAMIS* Co-ordinator | Grampian |
| Jo Campbell | Children's Epilepsy Specialist Nurse | Grampian |
| Gail Finlay | Parent Carer | Grampian |
| June Brown | Nurse Consultant | Grampian |
| | | |
| Michelle Morrison | *PAMIS* Co-ordinator | S. Lanarkshire |
| Margaret Johnston | Team Leader, Integrated Paed. Com. Nursing | S. Lanarkshire |
| Iain Wilson | Parent Carer/care officer | S. Lanarkshire |
| Linda Allan | Team Leader | S. Lanarkshire |

| | | |
|---|---|---|
| Ursula Corker | Parent Carer | Borders |
| Roy McConkey | Professor of Developmental Disabilities | Ulster |
| Chris Cullen | Director - Psychological Services | Stoke-on-Trent |
| Janet Cobb | Independent Consultant Learning Disabilities | |
| Dr Jeremy Turk | Professor of Developmental Psychiatry | University of London |
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