



Executive Summary

Invasive Procedures: Minimising Risks and Maximising Rights

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

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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

1 Background

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 (gastrostomy, nasogastric and jejunostomy) 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. 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 access to services to which they should be entitled (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, across individual authorities there may be different rules and

regulations. This obviously has major implications for the individual and also their parents and paid 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 many instances, may be 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 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.

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 noted above.

The principal aims of the study 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

2.1 SURVEY SAMPLE AND RESPONSE

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 based 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.

534 questionnaires were posted out with 168 subsequently categorised as withdrawals from the project. This resulted in a total of 366 questionnaires being distributed with 108 completed and returned, i.e. a 30% return rate. Seventy-eight professionals and paid carers and 30 family carers returned the questionnaire. Evidence suggested that a number of the remaining non-returned questionnaires were received by facilities and possible respondents not directly involved in the delivery of invasive procedures, though formal confirmation of this was not possible. However, we judge that the return rate was almost certainly in excess of the stated 30%.

2.2 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/Ileostomy care; 15 Urethral catheterisation; 16 Supra-pubic catheterisation; 17 Delivery of pessaries; 18 Injections; 19 Applying skin creams; 20 Oral/Nasal suctioning.

The 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 competent 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.

3 Data analysis

All quantitative data were entered into an SPSS (V15.0) dataset and analysed statistically. Results are presented for the entire sample (paid family and paid carers) and for each of these groups separately. Numbers in individual sectors, e.g. social care, health or education were too small to analyse separately. In the main report we document all figures fully, making clear the numbers on which percentages are based. For clarity's sake we here present just the percentages which have been rounded to whole figures from those appearing in Tables 1-10 in the main report.

Written comment by respondents were coded with respect to the principal themes emerging, i.e. recognition of extra duties and remuneration for staff; reference to training needs, staff resources, funding for training; issues related to legislation; policies and procedures in the care setting; job specifications highlighted; outsourcing of delivery of procedures; communication, relationships and partnership working.

4 Results

4.1 AGREEMENT ON WHAT CONSTITUTES AN INVASIVE PROCEDURE

There was a wide range of agreement with respect to whether any given procedure was regarded as invasive. The range of judgements of invasiveness was 94% to 22%. The three procedures judged most invasive were *manual bowel evacuation* (94%), *delivery of enemas* (92%) and *suppositories* (91%). *Tracheal suctioning* (84%), *tracheal tube replacement* (86%), and *urethral catheterisation* (86%). The least invasive were nebulising (19%) and administration of creams (22%) When family respondents judgements were compared with those of 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% Vs 63%), and long-term intermittent ventilation about which the judgement went in the opposite direction (81% Vs 60%, respectively).

4.2 BARRIERS TO DELIVERY OF INVASIVE PROCEDURES

The extent to which a barrier to the delivery of an invasive procedure was identified was dependent on the nature of that procedure and the status (family member or paid staff) of the respondent. Here we will summarise the relation between these three factors, i.e. the nature of the procedure, the type of barrier and whether the respondent was a family member or paid staff.

4.2.1 Limited staff resources

With respect to the three procedures judged most invasive (33% - *manual bowel evacuation*, 35% - *delivery of enemas* and 33% - *delivery of suppositories*), around one-third of staff considered limited staff resources a barrier to delivery of the procedure in their service setting. For *tracheal suctioning* and *tracheal tube replacement* just under 30% considered this barrier applied.

Family carers consistently judged the availability of staff resources as less of barrier than paid staff. A notable discrepancy was for *manual bowel evacuation* where only 9.5% of family carers Vs. 33.3% of paid carers considered staff

limitation a barrier. However, qualitative comments indicated that 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 a particular area of concern in relation to staff in hospitals who were often unfamiliar with the care required for patients with learning disabilities and as a result were heavily reliant on family carers to continue to provide care during hospital admissions.

4.2.2 Limited staff competence

Lack of staff competence was considered by paid carers a significant barrier to the delivery of several procedures. This was judged a barrier to both short-term and long-term intermittent ventilation, 54% and 56% of staff respectively. 59% considered lack of staff competence a barrier to both manual bowel evacuation (59%), tracheal suctioning (52%) and tracheal tube replacement (59%). With the exception of the two procedures regarded as least invasive, nebulising and application of creams (24% and 21%, respectively) delivery of most procedures were judged by 40-50% of staff to encounter barriers arising from lack of staff competence.

With the exception of gastronomy feeding, (50% judged lack of staff competence as a barrier), family carers did not judge this barrier as significant. For example, only one (4.5%) saw this as a problem in relation to tracheal tube replacement Vs 59% of staff. However, family carers, like paid staff, continually emphasised the importance of staff training to ensure effective delivery of invasive procedures. Some families also urged that as expert carers they should be involved in any person-specific training of staff required.

4.2.3 Staff attitudes

With respect to staff attitudes constituting a barrier, there were marked similarities to the results for staff competence. Staff attitudes were judged a barrier to both short-term (57%) and long-term intermittent ventilation (58%) of staff respectively. 57% considered staff attitudes a barrier to manual bowel evacuation and 58% to tracheal tube replacement. Staff attitudes were judged a particular barrier to giving injections, i.e. 60%. Again, the two procedures regarded as least invasive were nebulising and application of creams (23% and 24%, respectively). The delivery of most other procedures were judged to be affected by staff attitudes by 40-50% of staff.

Again, family carers' views indicated that staff attitudes were less of a barrier than judged by paid staff. However, there were two interesting contrasts. First, 50% of the former considered staff attitudes a barrier to gastrostomy feeding as against 31% of staff. The highest procedure for which staff attitudes were a barrier was unexpectedly one of the least invasive procedures, i.e. applying skin

creams. 39% of family carers judged this to be the case. Again, family carers urged that training could improve attitudes and reduce this as a barrier.

4.2.4 Service agencies policies and operating procedures

Though the pattern of staff judgements regarding the extent to which service agencies policies and operating procedures parallels those in relation to competence and attitudes, the percentage identifying this barrier was consistently lower. Nevertheless, in excess of 40% of staff judged that policies and operating procedures acted as barriers to short- and long-term intermittent ventilation (40% in both cases) as well as to the procedures involved in dealing with continence, e.g. manual bowel evacuation (43%) as well as tracheal suctioning and tracheal tube replacement (again 43% in both cases). Other procedures to which policies and operating procedures were judged to act as a barrier fell between 20%-39% of respondents.

Family carers' judgements fell consistently well below those of paid staff, with the exception of gastrostomy feeding where 37% judged policies and operating procedures to act as a barrier Vs. 32% of staff.

4.2.5 Service agency commissioners' operating procedures

Relative to the four preceding barriers, service agency commissioner's operating procedures were judged less of a barrier to the delivery of the procedures with typically 20%-30% of staff judging this to be the case for the main procedures regarded as invasive. The main exception was giving injections where 33% judged this to be a barrier. Nevertheless, commissioners' operating procedures were restrictive in some instances. Policies that prevent care staff from giving a person medication resulted in multiple agency participation where a person centred approach and relevant training might have allowed a single agency to carry out the task. The results parallel the outcome of service agency barriers where staff showed willingness but policies did not allow non medical staff to carry out even simple tasks like administering prescribed medication.

Family carers' view of commissioners' policies constituting a barrier again were consistently much lower than for paid staff, with two exceptions: 36% considered such policies presented a barrier with respect to gastrostomy feeding, while 29% judged this was the case for the administration of suppositories (compared, respectively to 12% and 27% for paid staff).

It possible that some family members were not in a position to judge what was happening at the level of commissioning, though clearly they may have been made aware of such information when questioning shortcomings in provision for their relative.

4.2.6 Consent issues

Paid staff and family carers made somewhat different interpretations of this question, the former taking consent to refer to that by the person with profound and multiple learning disabilities, while the latter implicated *their own* granting of consent for an invasive procedure to be administered to their relative. In several cases authorisation by the relative was given in their capacity as welfare guardian. It is important to note that many staff are unclear as to the powers of welfare guardians.

A minority of staff – around a fifth to a quarter - considered that the granting of consent by the person with profound and multiple learning disabilities presented a barrier, and where this was the case it tended to be in relation to the procedures deemed most invasive, e.g. tracheal tube replacement (23%) and delivery of enemas or suppositories (both 25%).

Families viewed consent as a problem in relation to their granting consent themselves, notably with respect to manual bowel evacuation (38%) and gastrostomies (31%). Consent was viewed as less important in relation to postural drainage (8%), nebulising, (8%) and the delivery of oxygen (8%). Families commented that consent was not an issue if there was confidence in the carers' ability to carrying out the procedure.

These figures are not as high as for some barriers related to staff practices, though there is sufficient concern to suggest that the granting of consent in relation to the delivery of invasive procedures merits clarification.

4.2.7 Care plans

For the principal procedures considered invasive, 20%-30% of staff judged care plans as a barrier to their delivery. Of course, such care plans will reflect the facilities' policies and operating procedures or indeed constraints arising from trade union intervention. Such barriers are, then, a further reflection of administrative barriers.

For families, care plans were seen as presenting barriers to gastrostomies, the application of skin cream and urethral catheters, 27% for all three procedures. Families felt 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. 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 administering 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.

4.2.8 Trade union interventions

In the context of the survey we were dependent on respondents giving specific examples of trade union involvement in determining the delivery of invasive procedures – which some indeed did do. It was not possible, however, to develop a comprehensive picture of the nature of union involvement locally and nationally, and the precise ways in which this facilitated or acted as a barrier to the delivery of the procedures. For the principal invasive procedures, staff reported that union involvement had created barriers for delivery of 21%-30% procedures. For example, such barriers were noted with respect to the delivery of enemas, suppositories and oral/nasogastric suctioning (30% in all cases).

In general, family carers noted either no union involvement (for 14/20 procedures) with barriers presented only for gastrostomies by 29% of family respondents (higher than for staff – 23%). Again, we might speculate that this information had been made available to them in the context of discussions with staff in relation to their own relative.

Respondents considered that union negotiations must continue and solutions be found especially in relation to remuneration for undertaking invasive procedures. Some considered 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.

4.2.9 Health and safety issues

A minority of respondents identified health and safety issues as presenting barriers to the delivery of invasive procedures, with concerns over litigation a primary consideration. For the more invasive procedures, a quarter of staff respondents judged health and safety issues with respect to urethral catheterisation (26%), supra-pubic catheterisation (24%), oral-nasal suctioning (26%) and manual bowel evacuation (27%). Other procedures such as intermittent ventilation (both short- and long-term) delivery of enemas, suppositories and pessaries and tracheal interventions were judged by about one-fifth of staff respondents to raise health and safety issues that could constitute barriers to delivery.

Again family carers on the whole did not raise health and safety issues as possible barriers, with the exception of gastrostomies (38%) and catheterisation (25%). Application of skin creams was also judged as entailing health and safety implications (25%).

5 Evidence of good practice

Throughout this review of staff and family carer views of barriers to the implementation of invasive procedures, we have noted that at all levels of the system, delivery of such procedures can, in varying degrees, be obstructed by a range of factors. Awareness of this state of affairs has led a variety of statutory and voluntary agencies to develop initiatives to ensure that such procedures can be effectively delivered. Some such initiatives are specific to invasive procedures. For example, a Fife family gave training on postural drainage and oral suctioning to staff coming into their home to provide the necessary care for their daughter. It also allowed them as family carers to leave their daughter in the care of staff knowing that they were well able to perform these tasks when necessary. Other examples of good practice were part of wider health care improvement strategies. For example, in Angus a “*Team Around the Child*” has been created. This team co-ordinates multi-agency involvement to meet the needs of children with complex disabilities.

The examples of good practice cited in the main report are generally local to a particular service or area, raising the issue of how such initiatives should be disseminated more widely, and indeed co-ordinated in a more comprehensive delivery strategy. Their effectiveness, too, merits consideration as in most cases we were not able to identify evaluative information that would provide a firm evidence base for their success.

6 Conclusions

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. Note, the main report provides details on the aim of each recommendation, who is responsibility for implementation, validation of effectiveness, the intended outcome, and the timescale for implementation.

AREA 1: POLICY AND PROCEDURES

Recommendation 1.1 Legal issues: 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.

Recommendation 1.2 Integrated Policies and Procedures: 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.

Recommendation 1.3 Policies and procedures of individual facilities: In the light of Recommendations 1.1 and 1.2 the implementation of the national guidelines should be reviewed and implemented at local level.

AREA 2: WORKFORCE DEVELOPMENT

Recommendation 2.1 Identification of workforce that deliver invasive procedures: In the light of national guidelines explicit specifications will be agreed by management, unions and the skills sector regarding job roles and expectations.

Recommendation 2.2 Education of staff: All relevant staff supporting people with profound and multiple learning disabilities, including non-nursing staff, should be trained in relevant invasive procedures.

Recommendation 2.3 Education and family carers: Any training programmes involving invasive procedures offered 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.

Recommendation 2.4 Training of transportation staff: 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.

Recommendation 2.5 Education within acute health care: Operating policies 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.

Recommendation 2.6 Education of acute care staff concerning consent: 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.

AREA 3: CARE PLANS

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

Recommendation 3.2 Care plans and family involvement: 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.

Recommendation 3.3 Acute care discharge protocol: 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.

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.

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