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Implementation of Part 5 of the Adults with Incapacity (Scotland) Act 2000: Analysis of written submissions to consultation

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Scottish Health Feedback

This research analysed written responses to a consultation on the implementation of Part 5 of the Adults with Incapacity (Scotland) Act 2000 (the “2000 Act”) conducted by the Public Health Division of the Scottish Executive Health Department. As part of the consultation, three documents were distributed to a range of organisations and individuals for their comments: a draft Code of Practice, Regulations on setting up an Ethics Committee, and a paper seeking views on the proposed treatments and safeguards to be regulated. This report provides a summary of the 78 responses received.

Main Findings

- There was, in theory, widespread agreement with the 2000 Act that ‘incapacity is not an “all or nothing” concept but should be judged in relation to particular decisions’. However, consultees thought the Act required a major shift in the attitudes of both professionals and public.
- There was a clear need and desire to link the 2000 Act more explicitly with the provisions of the Human Rights Act and to give greater consideration to the role and place of independent advocacy and independent legal representation.
- There was widespread concern about the emerging resource implications of implementing the Act.
- Some terms used in the consultation documents were repeatedly highlighted as undefined and problematic. In particular, the terms ‘emergency’ and ‘necessity’ were contentious and open to interpretation.
- Consultees felt there was an underlying assumption that adults with incapacity were ‘mentally disordered’. The boundaries with existing mental health legislation were often blurred. Several consultees expressed the opinion that the documents did not take sufficient cognisance of physical illness or the impact of treatments for physical illnesses on individuals’ capacity.
- The three draft documents received a general welcome overall. However, many of the concerns and issues raised were practical and operational, and it is arguable that their drafting would have benefited from closer consultation with practitioner interests at an earlier stage.

Introduction

The Adults with Incapacity (Scotland) Act 2000, passed in March 2000, enables decisions to be made on behalf of adults who lack the legal capacity to do so themselves because of 'mental disorder' as defined by mental health legislation, or the inability to communicate. Part 5 of the Act is concerned with provisions to safeguard the interests of such adults in relation to medical treatment and research. Between June and September 2001, the Scottish Executive Health Department consulted major stakeholders about three draft documents explaining the implementation of Part 5:

- A draft Code of Practice, intended to guide doctors and others who might find themselves in the position of responsibility for the health and treatment of an adult with incapacity;
- Regulations on setting up an Ethics Committee which will have the power to approve what research may be undertaken on or in relation to incapable adults;
- Regulations in relation to section 48 of the act, which deals with treatments where special safeguards will apply to protect incapable adults.

Response

Consultation papers were sent out in June 2001 to 817 individuals and organisations. Responses were received by the deadline from 78, 70 of which contained substantive comments. Of these, the great majority (61) represented the views of organisations, 8 came from individuals within organisations, and one from an individual with no stated organisational affiliation.

Four further substantive responses were received late and are not included in this analysis.

Comments on the Draft Code of Practice

Some consultees thought the Code of Practice "clear" and "well drafted", but others felt there was confusion both over key terminology used in the Act and over the interaction with other key legislation such as the 1984 Mental Health Act. The 2000 Act was complex and the draft Code of Practice appeared not to have served its purpose of explaining to practitioners succinctly and clearly how best to implement its provisions.

Table 1: Number of responses received by type of respondent

| Type of respondent | Number of substantive responses | Numbers invited to respond |
|------------------------------------|---------------------------------|----------------------------|
| Professional bodies | 21 | 74 |
| Health bodies | 12 | 127 |
| Local authorities | 9 | 72 |
| Patient/user/carer organisations | 9 | 61 |
| Voluntary organisations | 9 | 116 |
| Legal bodies | 2 | 151 |
| Public bodies | 2 | 27 |
| Other | 5 | 22 |
| Individual | 1 | 116 |
| Academic or research organisations | - | 20 |
| Commercial organisations | - | 10 |
| Scottish Executive officials* | - | 21 |
| All categories | 70 | 817 |

* Note that Scottish Executive officials received copies of the consultation documents for information purposes only.

Consultees requested detailed clarification and definition of such key words as 'benefit' and 'emergency' as well as guidance on the application of the doctrine of necessity and common law principles in more complex grey areas of practice. Even the 'medical practitioner who is primarily responsible' was not obvious in every setting, especially if more than one practitioner was involved with an individual. Assumptions in the document about the meaning of 'treatment' were felt not to reflect modern multi-disciplinary working.

The primary target audience for this Code of Practice will presumably be practitioners, as they will have to implement the 2000 Act. Some felt the Code provided too much description of the Act's provisions and too little guidance on what they would mean in practice and how they ought to be applied. Consultees suggested that a fundamental way of providing such guidance would be to include many more illustrations and scenarios.

Consultees suggested cross-referencing useful source documents or guidance from other bodies. GPs, dentists, psychologists, speech and language therapists and nurses all commented that redrafting of the Code could benefit from closer consultation with their professions, as there were many specialist points they believed should be taken on board. It was suggested also that significant rewriting was needed to make the Code accessible to the public and carers/relatives including people from minority ethnic communities.

Comments on the Draft Regulations for an Ethics Committee

One basic question raised was that of whether a new Ethics Committee on incapacity was actually needed. Furthermore, what practical consideration had been given to the arrangements and coordination that would be needed with other ethics committees, the Multi-centre Research Ethics Committees and the Local Research Ethics Committees in particular?

The bulk of comments received were in relation to Section 3 and the proposed membership of an Ethics Committee. The main issues were the need to have committee members with direct experience with groups affected by incapacity, and to involve a broader range of interests including disability and human rights activists, and representatives of different faith communities. While there was little comment on the method of approval outlined in Section 6, it was suggested that the current formula

would result in the Committee approving or rejecting research on the basis of its scientific rather than ethical merits, which seemed to defeat its purpose.

Comments on Draft Treatment Regulations and Safeguards

Consultees were in agreement with the stated proposals in relation to many of the questions posed in the draft Regulations and gave supplementary supporting comments or clarification. Treatments such as neurosurgery, abortion and sterilisation were more controversial and attracted diverse and sometimes polarised views. Indeed, whether abortion and sterilisation should even be considered as 'treatments' under the 2000 Act was brought into question.

One major issue was whether certain 'treatments' such as ECT (Electro-convulsive therapy) should even be considered as the terrain of the 2000 Act or that of mental health legislation. The issue was one of deciding which matters should be the subject both of legislation dealing with incapacity and that dealing with mental health matters, and which should be exclusive to either. Professional organisations with an interest in mental health issues such as the Mental Welfare Commission and the Scottish Association for Mental Health were clear about the boundaries, but others were less so.

Conclusions

Although these documents received a general welcome overall, the comments made about them were many and varied. Some of these related to issues with quite wide-ranging implications, such as interpreting the concept of 'incapacity' in practice; definitions of vital terms such as 'emergency'; and the interaction between the 2000 Act and other legislation, especially mental health and human rights legislation. Others related to the overall presentation of the documents, especially the Code of Practice, which was felt by some respondents to be less useful than other previously issued Codes. Numerous other comments related to detailed matters of drafting.

Since many of the concerns and issues raised were practical and operational, it is arguable that their drafting would have benefited from closer consultation with practitioner interests at an earlier stage.

Methods of Analysis

All response documents were converted to digital text form, with relevant information about the consultee attached. Responses were coded, using computer software for qualitative analysis (QSR N5), according to which part of the consultation papers they referred to, and where appropriate, particular themes within the content. All comments addressing a specific consultation document, part, section or paragraph were extracted in the form of coding reports and read together to identify main themes. Certain themes were common across the three documents and these were identified separately.

From this detailed analysis emerged a picture of the aspects of each document which aroused most comment and concern, from which quarters of opinion, and in what respects. A full report has been prepared presenting the findings from this analysis (see below for details). This report is essentially a presentation of the views of consultees, sorted by topic, analysed and summarised as accurately and faithfully as possible. It does not purport to make any judgements about where the balance of arguments lies, or make any recommendations about changes to the draft documents.

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