

Scottish Carers Alliance
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Adults with Incapacity (Scotland) Act 2000

1. Introduction: this paper will

- provide a very brief history to the Act;
- say what is meant by incapacity under the Act,
- set out the principles for that underpin the Act
- list the range of interventions covered, including the status that carers have under the Act,
- focus on health care decision making and the position of carers

2. History

This legislation sweeps away archaic laws that are hundreds of years old, inflexible and designed to protect the affairs of the well to do.

The definition of incapacity in law was that it was ‘all or nothing’ – you had it or you did not – it was totally inflexible and inappropriate. We know that for some people capacity fluctuates, sometimes over periods, sometimes within the space of a day; that some people recover from traumatic brain injuries, that for some the loss of capacity happens gradually over a long period of time; that some are capable of making certain levels of decision but not when matters become complex. Past legislation was therefore undermining of human rights and disempowering;

- It often meant that the funds of the adult were frozen and became inaccessible to the carer to manage without going to some expense or great expense if it became necessary to appoint a curator bonis;
- There was a lack of a legal way for carers to make welfare and health care decisions
- It meant that carers did not have to be consulted by health or social care professionals – although without going to the extreme of making an application for Guardianship under the Mental Health Act, they had no authority to make decisions either;

- It meant that financial powers of attorney were open to abuse because of a complete lack of safeguards
- it left doctors with no legal authority to treat people lacking capacity unless it was in an emergency;
- it left researchers in a legal vacuum in terms of seeking consent to medical research – researchers often misguidedly assumed that carers had legal authority to consent
- there was a lack of any means to seek a resolution where conflict existed between famil, professionals and the adult as to what should be done in certain circumstances.

3. What the Act has introduced

The new Act provides a legislative framework in which financial, welfare and health care decisions can be made – it is a resource to be used by carers (and in the absence of carers, local authorities) to support the care of adults with incapacity.

Interventions must be decision specific – there must be evidence that the adult is unable to make certain decisions/types of decision before a legal intervention can be put in place.

Interventions (slide)

- Joint accounts – either or survivor accepted if one signatory becomes incapable
- Powers of attorney: welfare/financial/joint
- Withdrawers scheme (intromission of funds) – application to Office of the Public Guardian to open separate account to manage funds of adult with incapacity.
- Intervention Orders (one-off): welfare/financial. Application to the sheriff court
- Guardianship order: welfare/financial/both. Application to the sheriff court

All parts of the Act are now being implemented with the exception of Part 4 which authorises registered care homes to manage the funds of residents with incapacity, when there is no one else available to do so – that comes into effect next April. Part 6 which brings in Intervention Orders and Guardianship Orders came into effect in April this year and Part 5 on Authority to Treat and Research came into effect on 1 July this year - so it is all still very new.

Definition of Adult

An adult means a person who has attained the age of 16 years;

‘incapable’ means incapable of

- a) acting or
- b) making a decision or
- c) communicating a decision
- d) understanding a decision
- e) retaining the memory of a decisions

An assessment of incapacity should be multi-disciplinary and should include the adult and the carer. This is stated throughout the Codes of Practice for the implementation of the Act. The main groups to benefit from the Act will be people with dementia, with learning disabilities, with acquired brain injury, with severe mental health problems, and those with severe communications problems caused by physical impairment such as stroke.

General Principles (Slide)

The Act strengthens the status of carers, particularly if they become legally appointed proxies. Their status is set out in the general principles that underpin the Act:

- Any intervention under the Act must be for the benefit of the adult
- It must be the least restrictive intervention to gain that benefit
- The present and past wishes and feelings of the adult so far as they can be ascertained must be taken into account
- Account shall be taken of the views of the nearest relative and the primary carer of the adult, in so far as is reasonable and practicable to do so;
- Account shall be taken of the views of any guardian, continuing attorney or welfare attorney of the adults who has powers relating to the proposed intervention; and

- Anyone appointed under the Act must do all that is reasonable and practicable to encourage the adult to exercise their skills and where possible learn new skills.

4. How will the provisions help carers:

The Act has introduced a new welfare power of attorney – to be appointed by you or I whilst still competent. If we want someone else to make health care decisions for us if we become incapable then we must state that authority specifically in the document granting powers of attorney. We might want to make it very specific eg only in certain circumstances or in relation to specific treatments; we might specify that we would want the attorney to make all welfare decisions on our behalf – this would allow access, for example, to Direct Payments for care services.

The Act has created a new Welfare Guardianship intervention – carers can apply to the Sheriff Court to be a welfare and or financial guardian to make major and ongoing decisions with regard to health, welfare and or finances of the person they care for. Again the application must specify the powers requested and must state why they are needed. Carers with welfare guardianship powers will also be able to access Direct Payments.

Carers may also apply to the Sheriff Court for an intervention order for a one-off treatment decision, such as a serious operation that should not be delayed. However, for example, if it is likely that the adult will be unable to make treatment decisions over a period of time then a welfare guardianship order may be more appropriate, - an interim guardianship order might be made if it is important that a treatment decision should not be delayed. It is therefore important to think carefully about what type of order is needed to avoid expense and duplication of effort – the procedures for both intervention orders and welfare guardians are much the same i.e. two doctors (one specialist) must have assessed the patient and signed the certificates, and a report has to be submitted to the Sheriff from the MHO.

Once appointed, you, the proxy should notify all relevant health and social care professionals and ask that the information is placed prominently in the file of the adult with information about how you can be contacted if decisions have to be made. Even where the carer has no legal powers the doctor still should consult with you as far as is practicable and reasonable to do so – so carers should ensure that doctors know how to contact you. The Act reinforces the role of carers as partners in care, if they are to care effectively then they need to be involved

in medical decision making and to understand the treatments that are being proposed. Carers often have a great deal of information about the medical history of the person they care for to assist the doctor and this has not always been listened to as well as one would have liked in the past.

If a carer has not been consulted and they feel that it would have been practical to do so then the professional is open to a challenge. Emergency decisions may mean that it is not reasonable to consult with the appropriate relative, but such circumstances will be unusual.

5. Health care decision making and carers

Involvement of carers in assessment of capacity

The Code of Practice on authority to treat sets out the procedures that medical doctors should follow when assessing a patient's capacity to consent to treatment decisions. This includes a multi-disciplinary assessment, involving the adult and the carer, as well as any other relevant professionals or independent advocate. The doctor is required to place information about consultation with the carer on the certificate of incapacity. Certification has to be reviewed every 12 months. The assessment should only take place where there is evidence that the patient is unable to give informed consent and it may relate to a number of ongoing treatment decisions. Best practice in the code suggests that assessment is carried out as part of the development or revision of the care plan.

Involvement in medical decision making

Where a carer has an application for an intervention or guardianship order pending that relates to the medical treatment under consideration, the doctor will be prohibited from going ahead unless the patient is likely to suffer from serious deterioration.

Where a carer has an intervention order or welfare guardianship that authorises medical decision-making then the medical practitioner should obtain their consent where it is reasonable and practicable to do so.

Where the doctor primarily responsible for the treatment has consulted with the proxy and the proxy disagrees with the doctor then the doctor shall request the MWC to nominate a medical

practitioner from a list of specialists to give an opinion on the medical treatment proposed. This doctor is referred to as the ‘nominated practitioner’.

This doctor must consult with the proxy and anyone else the proxy suggests e.g. an independent advocate or another relative, as well as the doctor with primary responsibility. If the two doctors agree then the treatment can go ahead – however the proxy may still object and may make an appeal to the Sheriff and then, with leave of the sheriff, to the Court of Session. If the nominated doctor agrees with the proxy and disagrees with the doctor primarily responsible, then if the doctor primarily responsible feels strongly enough then he/she may appeal in the same way. It should also be noted that ‘any person having an interest’ can also object to a treatment decision and appeal to the Court of Session. Taking a case to the Court of Session is a costly business and the costs could land on the carer. It is the intention of the Act that the vast majority of disagreements will be resolved at a much earlier stage.

Authority for research

There are now strict criterion, which have to be observed by researchers in conducting research that involves adults who are unable to give informed consent

Consent has to be obtained from ‘any guardian or welfare attorney who has power to consent to the adult’s participation in research, or where there is no such guardian or welfare attorney, from the adult’s nearest relative’.

5. Issues arising

- 5.1 Definition of primary carer/ next of kin/nearest relative - this will eventually be changed in line with the definition under the Mental Health Bill
- 5.2 Conflicts between who should take precedence – primary carer or next of kin – conflicts over who is next of kin – eg. status of next of kin living abroad – e.g. status of same sex partner for six months or more is considered next of kin. The Sheriff is able to invite the views of anyone he thinks fit.
- 5.3 Where professionals have serious concerns about neglect or potential abuse of the adult from someone appointed as welfare attorneys or guardians – they can ask for the

intervention of the MWC, and go to the Sheriff to request supervision by the local authority, and to the public guardian in the case of someone appointed to manage finances.

5.4 The cost of making application to court falls on the carer in the first instance and the position regarding legal aid is unclear and is an issue that is being investigated. There is no standard fee for medical certificates for legal services. They can vary considerably. Cheapest if we all appoint welfare and financial attorneys (normally costs less than £100) or on the financial front, to apply to be a withdrawer, which costs nothing and the Public Guardian's Office will help fill in forms over the telephone.

Action is needed :

To develop local information strategies to get information across to carers that the Act is here to benefit the person they care for and to make life easier for carers when faced with making decisions that the person they care for is unable to make for themselves.

To information and training across to health and social care professionals who are in the front line – they need to understand the benefits of the Act and how it can be used in a person-centred way to resolve problems that were intractable prior to the Act – and to feel confident about that.

It is heartening to know that lead officers in each local authority are taking this forward with interagency implementation teams. The Scottish Executive's initiative, the Learning from Experience Project which I lead is here to do just that – to identify issues and problems arising, to look at what might be done to improve matters and to put forward recommendations to the Scottish Executive. We are also keen to hear about when the Act is working well and carers feel it has helped. I have brought a small leaflet about the Act and an information sheet about the project and where to contact me. I shall look forward to hearing from you.

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