

‘Who Decides & How?’ – Making Medical Decisions

**An information booklet
for parents and families of children
with intellectual disabilities**

Your Questions Answered



INCLUSION IRELAND

Promoting the rights of people with an intellectual disability

Inclusion Ireland is a national voluntary umbrella organisation working to promote the rights of people with an intellectual disability in Ireland to ensure their full and equal participation in society. **Inclusion Ireland** was founded in 1961 and has become the co-ordinating body for over 160 organisations providing services and supports to almost 27,000 people with an intellectual disability that live in Ireland.

Inclusion Ireland provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to Government and statutory bodies, to other relevant groups as well as to the general public. **Inclusion Ireland** campaigns for changes in services and legislation that will improve the quality of life and participation for people with an intellectual disability in Irish life.

Contents

Introduction		7
Chapter 1	Explaining “Consent & Capacity”	11
Chapter 2	Deciding on the Capacity of a Person	17
Chapter 3	Ward of Court and Power of Attorney	21
Chapter 4	Approaches in other Countries and Future Development in Ireland	25
Conclusion		29
Appendix 1	Useful Contacts	33

Introduction

Healthcare staff care for people in increasingly busy wards and crowded surgeries. We are left with less time for each individual patient than we would like. To maximise our time we often make presumptions on certain basic issues. One of these is consent. If a person comes to see us we presume that they are consenting to become a patient with all this entails. We may also assume that a person with an intellectual disability is unable to consent. Either may be incorrect depending on the individual, their disability and the circumstances. It is important to doctors that each patient's autonomy is protected. We want patients to understand our actions and interventions and agree to them based on this understanding. Assuming that someone understands us when they don't and presuming that someone is unable to understand us when they do are opposite sides of the same coin. Both are damaging to a person's autonomy. Thus all of us as clinicians who interact with patients who have an intellectual disability need input from patients and, where necessary, their advocates. Working with people who have an intellectual disability who may need medical intervention requires a coalition of supports. This coalition must involve the patient, the doctor and patient advocates. The latter may be family, friends or other carers. To be effective advocates people need information. I am therefore delighted that **Inclusion Ireland** has produced this booklet. I hope that it will be a help to people with intellectual disabilities who require medical treatment and to their families and other carers.

John Hillery

Consultant Psychiatrist

Chairman of the International Association of Medical Regulatory Authorities

Former President of the Medical Council of Ireland

Chapter 1 Explaining Consent & Capacity

Explaining Consent and Capacity

Question: Who has the right to make decisions on their medical care?

Answer: All persons in Ireland have a right to give consent to medical decisions from the age of 16.¹ The parents of a child aged 16 cannot overrule their consent; they can however overrule a refusal of consent for a medical treatment. Where a medical decision has to be made relating to a child, the right to make the decision lies with the parents. There is no specific procedure for making medical decisions on behalf of people with intellectual disability.

Question: What is “consent?”

Answer: In general a medical decision cannot be made without the consent of the person who is having the treatment. There are very few definitions in Irish Law about what constitutes consent. *The Mental Health Act 2001* defines informed consent as being given freely and not under threats or inducements, and where the patient has been given enough information in a way they can understand and can understand the nature, purpose and likely effect of the treatment. This means what exactly the treatment is, what the treatment is designed to do and what results it might have. The patients should also be able to understand the likely effects of refusing the treatment.

Although this definition applies solely to psychiatric treatment and not other procedures it is a useful tool in looking at informed consent in other areas of medical treatment.

Question: How is consent obtained?

Answer: It is important to note that the explanation must be given to the patient in a way that they will understand. It may not be appropriate to use complex medical terminology when discussing medical treatment with a person with an intellectual disability.

¹ Section 23 of the Non-Fatal Offences against the State Act 1997.

It may be appropriate to use diagrams or drawings to explain a medical procedure.

Consent may be implied, verbal or written. Implied means that the therapist does not ask the patient directly if they agree to an intervention (eg examination) but implies from their cooperation that they consent. Verbal and written consent are self explanatory. Doctors usually accept verbal consent for non-invasive tests and treatments (e.g. x-rays, blood tests and medication) but should get written consent for more invasive and/or riskier interventions such as surgery under anaesthetic.

Question: What happens if medical treatment is given without consent?

Answer: To treat someone without his/her consent amounts to the criminal offence of assault.

There are some exceptions to this rule:

- Emergency treatment; where the medical treatment is necessary to save the life of the person but consent cannot be communicated
- Where the medical practitioner is acting under a court order; for example under a ward of court order.

Question: What is "capacity?"

Answer: A person lacks capacity in relation to a matter if at the material time he/she is unable to make a decision for himself/herself in relation to the matter. Capacity must be present in a person before consent can be given by him or her. In Ireland there is a presumption of capacity. This means that every person is presumed to have the capacity to make individual decisions. This presumption of capacity can only be taken away if proved to be lacking.

The person in question does not have to prove his/her capacity to consent. It is important to remember that a person does not lack capacity simply because they make a bad decision or a decision another person would rather they wouldn't.

Question: Can I give consent for my son or daughter?

Answer: Consent can be given on behalf of their son or daughter until they turn 16. After this the consent can only come from them. There is no provision in law to allow people to make medical decisions on behalf of other family members.

This poses a problem for medical practitioners in getting consent for procedures where a person is over the age of 16 and is deemed to lack capacity. Where such problems arise, medical practitioners rely on medical ethics to guide them. This is discussed further in Chapter 2.

Question: Can I refuse to give consent for my son or daughter over the age of 16?

Answer: As above, the Ethical Guide issued to all doctors by the Medical Council states that family members should be consulted, however the decision rests ultimately with the medical practitioner to make. S/he will act in the best interests of the patient in making general medical decisions.

Question: What if the person makes a “bad decision”?

Answer: It is worth remembering that just because a person makes what would be considered a bad or unreasonable decision, does not mean that they lack the capacity to have made the decision at all.

Chapter 2 Deciding on the Capacity of a Person

Deciding on the Capacity of a Person

Question: How are doctors required to communicate with patients?

Answer: Doctors are required to fully explain treatments to patients in non-technical terms.² Patients should be encouraged to ask questions about a condition or treatment. If a doctor feels that a patient does not understand the explanation it is usual for them to ask for permission to speak to a family member.

Question: When should a decision be made that a person lacks the capacity to make a decisions?

Answer: As discussed above, there is always a presumption of capacity which has to be disproved. It is a serious matter to have someone declared incapacitated, as exercising free will is a fundamental human right. Therefore somebody making decisions on your behalf is exercising a right on your behalf. The medical profession have stated clearly that "Disability does not necessarily mean lack of capacity."³

Question: What does a doctor or nurse do if an adult cannot consent to a treatment?

Answer: The most recent Medical Council Ethical Guide⁴ states that "if a person with a disability lacks the capacity to give consent, a wide-ranging consultation involving parents/guardians and appropriate carers should occur."

The ethical guidelines state that a doctor should seek a second opinion before carrying out treatment on complex issues.

Question: What will parents be consulted on?

Answer: Parents will be consulted on decisions that their son or daughter doesn't have the capacity to make while they are under

² The Medical Council *A Guide to Ethical Conduct and Behaviour* 6th Edition 2004 Pg.13.

³ The Medical Council *A Guide to Ethical Conduct and Behaviour* 6th Edition 2004.

⁴ 2004.

the age of 16. If a person aged over 16 has the capacity to make a decision for themselves then the involvement of parents should be with his/her agreement, as with any other patient.

Question: Will friends be consulted on medical decisions?

Answer: The medical ethics state that only family members and appropriate carers will be consulted. Therefore only people with knowledge of the person's needs will be consulted.

Question: What if family members disagree with the doctor or each other on the best form of treatment for a person who lacks capacity?

Answer: The Ethical Guide does not expressly state what approach should be taken in the event of disagreement between doctor and family members. However if there is disagreement a second opinion could be sought or another doctor asked to take over the case.

Question: If a person is found to lack the capacity to make a medical decision, should all medical decisions be made for them in future?

Answer: Each medical decision should be made in its own right. Some people may be able to make decisions about minor medical decisions such as a medical examination or a visit to the dentist, but may not have the capacity to decide on a major operation. It should not be assumed that people cannot make a decision because they could not take a particular decision in the past.

Chapter 3 Ward of Court and Power of Attorney

Ward of Court and Power of Attorney

Question: If a person is a ward of court, who makes decisions about their medical treatment?

Answer: If a person is ward of court and they need medical treatment for which a consent form is required by the hospital, the President of the High Court should approve the procedure.⁵

For regular medical treatment such as general examinations or treatment of fractures or such injuries the examining doctor will usually get permission from the office of the Wards of Court.

For less usual treatment or so-called “controversial” treatment the President of the High Court will want to make the judgment directly. This would include invasive procedures such as feeding tubes or major surgery.

Question: How does the President make his decision?

Answer: The President will make a decision on what is in the best interests of the patient.⁶ The thoughts of the next of kin and other family members are considered but will only be taken into account if the President of the High Court believes that they are in the best interests of the ward of court.

Question: What happens if there is an emergency situation?

Answer: If there is an emergency then there may not be time to seek approval from the President of the High Court. If this happens then medical treatment should be carried out in the normal way and medical treatment sought. A medical practitioner is entitled to treat the person in order to preserve his/her life or health.

Question: Can the court refuse to grant permission for medical treatment?

Answer: Yes in certain circumstances. The court will often take into

⁵ In Re MB 1997 2FLR 426.

⁶ In Re a Ward of Court (Withholding Medical Treatment) (No. 2) 1996.

account what decision a person might have come to in deciding whether to give consent.

Question: What is enduring power of attorney?

Answer: Enduring power of attorney is a legal device. It allows a person to choose another person to act on their behalf if they become incapacitated. It is useful in order to avoid a Ward of Court application being made in the future.⁷

Question: Is enduring power of attorney appropriate for a person with intellectual disability?

Answer: Enduring power of attorney is unlikely to be used by people with intellectual disability because the person choosing the attorney (The Donor), has to have the mental capacity to do so.

Question: How does a person show their capacity to give a power of attorney?

Answer: In order for a person to give a power of attorney they must show that they do have the capacity to understand by getting statements from a doctor and solicitor. The person must show that they have the capacity to give instructions.⁸ The solicitor must be happy that the person isn't under the influence of another person.

Question: What decisions can an attorney make?

Answer: An attorney may make decisions about property, business, and financial affairs and personal care decisions such as where the donor lives and decisions about diet and rehabilitation. The attorney must always act in the best interests of the donor and always consult family members about decisions. At all times the court supervises the decisions.

The attorney does not have the right to make health care decisions such as giving consent to surgery but can make decisions about what rehabilitation may be appropriate.

⁷ FLAC, *The Enduring Power of Attorney*, January 2007.

⁸ *Law Society of Ireland, Enduring Powers of Attorney Guidelines for Solicitors* May 2004.

Chapter 4 Approaches in other Countries and the future in Ireland

Approaches in other Countries and Future Development in Ireland

Question: Do other countries take other approaches to the issue of medical consent?

Answer: The approach in Britain is similar to the present Irish system.⁹ In the British system, nobody can give consent for another adult, and if a person lacks the capacity to make a decision, then the medical professional is legally responsible for deciding on treatments and acting in the patients best interests. However medical professionals are encouraged to consult with family member and the friends of person in deciding on treatment.

In Scotland, where the medical practitioner is of the opinion that the patient lacks capacity then s/he may do what s/he thinks is reasonable to safeguard the health of the patient.¹⁰

In the Canadian province of British Columbia, a system of supported decision making is available. In this system a person with a disability can enter into a representation agreement with a support network. The support network is comprised of people whom the person with a disability trusts. A medical practitioner is informed of this support network and that the network has authority to represent the person it is supporting and assist him/her in making medical decisions.

Question: Are there likely to be any changes to the law in Ireland?

Answer: In February 2007 a private member's bill was sponsored by Senator Joe O'Toole and Senator Mary Henry in the Senate on the issue of adult guardianship. The Bill was called the *Mental Capacity and Guardianship Bill 2007*.

The Bill includes much of the Law Reform Commission's recommendations in its paper "Vulnerable Adults and the Law" as regards replacing the overarching system of Wards of Court with a system of guardianship around specific issues.

⁹ *Seeking consent: working with people with learning disabilities*, Department of Health (UK).

¹⁰ S. 47 *Adults with Incapacity* (Scotland) Act 2000.

Due to the General Election of 2007 the Bill did not pass into law. However the current Government's Legislation Programme includes a Mental Capacity Bill to be published in 2008.

Question: What changes would the bill make?

Answer: It is hoped that the Bill, if enacted would bring in a definition of capacity, abolish the Ward of Court system and allow for personal guardians.

Question: Are there any International laws?

Answer: The Convention on the Rights of Persons with Disabilities was signed by Ireland in March 2007 and has a section on capacity.

Article 12.2 says *"States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life"*.

It is important that Ireland bring in legislation on capacity so that we can ratify this convention.

Conclusion

It is very important that people with intellectual disabilities have their rights protected in their interactions with healthcare professionals. A decision on their ability to give consent must be based on an assessment of the individual and not based simply on a perceived presence or absence of general intellectual disability. Any removal of a person's right to make their own healthcare decisions should only be done as a last resort in response to clear evidence that the person does not have the capacity to make the decision themselves.

The role of the family and other carers in assisting medical professionals is important. Family members and carers will often be in a position to understand what a person would want and whether a person is comfortable and happy in a particular situation. However at present there is no legal right for a family member or carer to make medical decisions for a person who lacks capacity. Although we have seen that medical ethics advises consultation, at present in Ireland it is the responsibility of the medical professionals to make the final decision.

It is clear that Ireland requires a form of supported or substitute decision making legislation. It is vital that people with intellectual disabilities have their autonomy protected equally to that of people without a disability. This means that the present system will have to change and that an adult person with a disability who does not have the capacity to consent can have a guardian or a panel of guardians to assist in or make decisions for them.

Such legislation would formalise what is already happening in many situations, whereby a family member is required to sign a consent form for medical treatment on behalf of a person with an intellectual disability. It should also ensure that the consent of a person's family would only be sought in situations where it was clear that the person who was being treated lacked the capacity to consent.

Appendix 1 Useful Contacts

Medical Council of Ireland	www.medicalcouncil.ie/
UN Convention on the rights of People with disabilities	www.un.org/disabilities
Ward of Courts Office	www.courts.ie
Canadian Association of Community Living	www.cacl.ca
Citizens Information	www.citizensinformation.ie/

References

1. '*Wards of Court in Ireland*' Dr. Anne-Marie O'Neill 2004.
2. '*Who Decides and How*' Inclusion Ireland 2003.
3. '*Ethical Issues*' Andrew Goddard 2006.
4. '*Guidelines for mental health & learning disabilities nursing*' United Kingdom Central Council for Nursing 1998.
5. '*A Guide to Ethical Conduct and Behaviour*' 6th Ed. The Medical Council of Ireland, 2004.
6. '*Seeking consent: working with people with learning disabilities*' Department of Health (UK) 2001.
7. '*The Enduring Power of Attorney*' Free Legal Advice Centre 2007.
8. '*Report on Vulnerable Adults and the Law*' Law Reform Commission 2006.

Notes