

Submission to the Oireachtas Justice Committee on Proposed New Mental Capacity Scheme

**- August 2011: Inclusion Ireland,
National Association for People with Intellectual Disability in Ireland**

1. Introduction

1.1. Inclusion Ireland is the largest national organisation representing and promoting the interest of people with intellectual disability, their families and service providers in Ireland. 160 affiliated organisations representing 25,000 people with intellectual disability. This year Inclusion Ireland is celebrating 50 years of pioneering work 1961-201. The founders rejected the practise of institutionalising people with intellectual disabilities and instead set out to create the supports, services and the legislation necessary to make sure people could live in their own communities, have their rights respected and upheld, including the right to make decisions. While much has been achieved there is still one outstanding black spot on the legislative front namely the lack of modern capacity legislation.

2. Context

2.1. For centuries people with intellectual disabilities have had their basic rights to self-determination systematically abolished by others taking on the legal authority to make decisions for them. The UN Convention on the Rights of Persons with Disabilities 2007 brings such laws and thinking into question, in particular Article 12 which declares that States Parties...

1. reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards

2.2 Article 12 implies a wide range of supports to assist people in exercising legal capacity. It means that under international law people with even very significant intellectual and other disabilities have a right to support in decision-making such as: assistive technology, interpreters, a recognised support network or circle of friends. Accessing needed support to make decisions is now recognised as being at the heart

of exercising one's right to self-determination, and of the right to be equally recognized as full citizens before the law. Article 12 also raises profound questions for legal and social policy which Ireland has yet to tackle. The focus of international law is to ensuring everything possible is being done to establish the supports needed for a person to exercise their legal capacity. Ireland must follow suite.

3. Current Legislation in Ireland

3.1. The Lunacy Regulation (Ireland) Act 1871 is the current legislation used in Ireland in cases where capacity is an issue. When an application is made to have a person made a Ward of Court. The decisions on capacity are made by the Judge alone. Wardship applications are rarely contested so there are no reported cases which analyse the factors which were taken into account when capacity was being assessed. A Ward of Court is denied the right to vote, to make a will, to travel abroad, to marry. Furthermore, Wards of Courts who are involuntarily detained in a psychiatric hospital or approved centre are not covered by the Mental Health Act 2001 and have no right to a Mental Health Tribunal

3.2. Inclusion Ireland has been deeply concerned about the inadequacies of the 1871 Lunacy Act for many years and has argued for new legislation to provide for decision making by adults with intellectual disability. Our publication of 2003 'Who Decides and How' outlined clearly our concerns with the current Wards of Courts system and called for its radical overhaul. Inclusion Ireland broadly agrees with the Law Reform Commission recommendations in its report the 'Law and the Elderly' (2003) which dealt with the protection of vulnerable people in particular those who have decision making disabilities. Since then there have been a further two major reports from the Law Reform Commission in 2005 and 2006 refining the thinking on legal capacity.

4. The Compelling Case for Reform

4.1. People with intellectual disability do not have clear rights to make decisions, the law on deciding who has decision making capacity is totally inadequate and the arrangements for supported decisions making, as occurs in other countries such as Canada and Germany are nonexistent. This means that the rights of people with intellectual disabilities may be infringed and creates major practical difficulties for people themselves, their parents, families and carers and service providers.

4.2. In practise decisions frequently are made on behalf of adults with intellectual disability. There is no formal system of assessment of the capacity of a person to make a decision unless there is an application to have the person made a Ward of Court which is rare (115 people with an intellectual disability were made Wards of Court out of over 2000 in 2010).

4.3. The day to day living decisions tend to get made on an informal basis. The person making the decision may not recognise that the person has any decision making capacity or may not attempt to establish what that capacity may be. They may have a paternalistic approach based on an assumption that they know better. More often it occurs because the person has limited capacity and a decision has to be taken. In such cases those making the decision may have no legal protection for decisions taken in good faith and in the absence of clear laws.

4.4. The decisions which pose the greatest difficulties are, in the experience of Inclusion Ireland, ones involving money and property, medical treatment, sexual relations and where there is a difference of opinion between parties such as:

1. A mother advised to make her daughter a Ward of Court in order to have a gynaecological procedure undertaken. The mother did not wish to do so;
2. Doctors seeking consent for a routine operation from a distant relative who had limited contact with the person. In cases 1&2 a person may have been denied a beneficial but not absolutely necessary operation because it was deemed there was no one to take the decisions;
3. An adult with an intellectual disability being made a Ward of Court after receiving an award of €70,000 following a car accident. The person had capacity in many areas but required some support to manage his finances.
4. A separated parent insisting on visitation rights to see his adult son yet the son had expressed a clear wish not to have such contact;
5. Parents with intellectual disability involved in child care proceedings as they are deemed incapable of looking after their children;
6. Children of a mothers with an intellectual disability cannot be put forward for adoption on the grounds the woman lacks capacity to consent;
7. A sexual relationship between two people with intellectual disability outside of marriage may constitute a criminal offence;
8. Adults with limited capacity prevented from seeking refunds for illegal health charges;
9. People with intellectual disabilities required to be made a Ward of Court after they had received awards from the Residential Redress Board;
10. Agents (family or a service provider) being appointed for Disability Allowance without any assessment of capacity of the person to manage their money;

4.5 Other areas where difficulties arise relate to service providers/professionals who are unsure of about consulting with families about decisions that need to be taken concerning their adult children. These may range from the mundane to the very personal. Families who are actively involved in the support of their adult son or daughter who is in residential care may find themselves excluded from the decision making process. Applications to make a person a Ward of court can be made without the family being notified and while notice is served on the person he/she may not

have had the application process explained in a way that is understandable to him/her.

5. Scheme of Mental Capacity 2008: Recommendations

5.1 In 2008 Inclusion Ireland welcomed the new Scheme for Mental Capacity drafted by Department of Justice and that a consultation process was taking place at this stage rather than when a Bill was prepared. Inclusion Ireland made a submission to the Department on the new Scheme but is unaware of any changes that have been considered as a result of the consultation process. In 2008 Inclusion Ireland recommended that the scheme be renamed the Legal Capacity Scheme/Bill. The term “mental” is no longer appropriate. Other terms such as *care protection, best interest and guardianship* should also be revisited. There is a paternalistic aura around some of the phraseology.

5.2 Summarised below is the Wards of Court System, proposals of new Scheme, their likely effect and Inclusion Ireland’s recommendations for change:

| Wards of Court Inclusion | New Scheme | Likely Impact | Recommendation |
|---|---|---|---|
| Jurisdiction: The President of the High Court/ Office of the Wards of Court and Circuit Court | High Court and Circuit Court | Old system but new name. Judge makes decisions. Office of Public Guardian replaces Office of Wards Court. Costs of application must be borne by applicant | New Legal Capacity Board independent of Courts & multi disciplinary should make decisions .To be overseen by Office of the Public Guardian. Proposed by LRC Report 2006 Example Mental Health Tribunals |
| The Court is satisfied that a person is on the basis of medical evidence available mentally incapacitated. No definition of capacity | The Court can request ‘expert’ reports as it considers necessary whether medical social and healthcare or financial. Definition of capacity | Only medical and psychological reports Cognitive ability (IQ tests) recognised “experts” | Balanced report in line with social model including testimony from family and others who know the persons. Telling the persons story over time and why certain decisions make sense |
| Appointed Committee of the Person has to follow the directions of the Court one or two persons (can be family) appointed as the Committee | Personal Guardian appointed to make decisions | Increase in numbers of personal guardians | Should be more than one person appointed as Guardian as a safeguard. Emphasis on supporting rather than making decisions |
| Applications can be made by family | An application may be brought without | A personal guardian who has an order for | All applications should be made on notice in a manner |

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| <p>members, care staff solicitor</p> <p>Notice of the application must be served on the proposed Ward. Person can object in writing (rarely happens)</p> | <p>notice by 1)the donor of Enduring Power of Attorney re: that power, 2) a personal guardian, 3)the public guardian 4) a person named in existing court order. 5)made on notice by a wide range of people</p> | <p>a specific aspects can achieve a wider degree of control by stealth</p> | <p>that is understandable to the person involved. Supports to be provided both (legal & advocacy)</p> |
| <p>Best interests are decided by the Court</p> | <p>Court can make additional orders if it is in the “best interests” extend scope</p> | <p>Best interests often decided by ‘expert’ reports, IQ tests. Easy way out, ignores consent No defining of best interest</p> | <p>Best interests incompatible with guiding principles. <i>A person is not to be treated as unable to make a decision because he/she makes an unwise decision.</i> Regard be given past present wishes/choices</p> |
| <p>Movement of the person’s capacity to the High Court/Committee Person loses “person hood”</p> | <p>Functional approach and issue specific.</p> | <p>Capacity is examined in the context of particular decisions, personal welfare, property & financial affairs</p> | <p>Encourage greater use of supported decision making model encouraging a wide range of supports to assist people in exercising legal capacity</p> |
| <p>Notice is served (in writing) proposed Ward may object in writing generally through a solicitor</p> | <p>Notice is served in writing. A person may object in writing before expiring period.</p> <p>Scheme to provide for legal representation where required</p> | <p>Onus on the person often will not know applications been made. Very difficult for those with intellectual disability</p> | <p>A suitable trained person should visit the person and his family where appropriate to outline procedure</p> <p>Role for independent advocates</p> |
| <p>Ward submits suitable medical evidence that he she has recovered in order to secure a discharge order -very difficult to overturn</p> | <p>A decision can be reviewed any time on application. Or at maximum 36 months</p> | <p>Not many reviews will take place outside of 36 mts .Very long time period. Current Wards - will they have a review?</p> | <p>More frequent reviews at least every 24 months</p> |

5.3. Article 12.2 of the UN Convention on the Rights of Persons with Disabilities says “States Parties shall recognise that persons with disabilities enjoy legal capacity on

an equal basis with others in **all** aspects of life”. The new Scheme states that in particular this Act shall not affect the Law concerning

- a. Capacity and consent to marriage or civil partnership
- b. Consent to a judicial separation, a divorce or a dissolution of a civil partnership
- c. Consent to a child being placed for adoption
- d. Consent to the making of an adoption order
- e. Consent to have sexual relations
- f. Voting at an election or at a referendum
- g. Acting as a member of a jury

5.4 It appears that proposed legislation is opting out rather than dealing with these more complex areas. The failure to address marriage and sexual relations abandons people with an intellectual disability to an ongoing vulnerability in regard to section 5 of the Criminal Law (Sexual Offences) Act 1993. This law makes it a criminal offence to have sexual relationships with people who are mentally impaired. The aim is to protect people with intellectual disabilities but it is unduly restrictive. This legislation was passed after a Law Reform Commission Report on Sexual Offences against the Mentally Handicapped (1990) proposed that this not be a criminal offence.ⁱ¹

6. Assisted/ Supportive Decision Making.

6.1 The essence of supported decision making is to enable people to maintain full legal capacity while availing themselves of legally recognised access to supports. Supported decision making has been primarily articulated in Canada (British Columbia). Prof Michael Bach of the Canadian Association for Community Living, in an address to Inclusion Ireland Parents Seminar in 2007, describes it as when:

“An individual’s full legal capacity is fully recognised if they can demonstrate to others their will and intent, and if not, if their ‘personhood’ can be articulated by others designated as sufficiently knowledgeable to understand a person’s unique communication forms and life history. Competency is attached to the decision making process, and not to the person, thus circumventing some of the issues associated with ‘autonomous’ decision making, where it is the person’s intellectual and communicational abilities which are assessed as capable or not.”

6.2 With supported decision making, a personal network of people is mandated as the trusted authorities to assist a person in making decisions (which assistance can include interpretation of a person’s will, the telling of a person’s narrative and why certain decisions make sense, etc.). In British Columbia over 4,000 Legal Representation Agreements have been drawn up since 1999. A representation

¹ The Law Reform Commission is currently preparing a Consultation Paper: The Law of Sexual Offence: Capacity to Consent. The aim is to make recommendations for the reform of the Criminal Law (Sexual Offences Act) 1993.

agreement allows people with intellectual disabilities and the elderly to name people they want to help them make decision on their behalf if they need assistance due to accident, illness or disability. The benefits of this system is that is formalises informal decision making without going down the guardianship route. Enhanced Representation Agreements are available to deal with health financial and personal care decisions which require a lawyer and have a higher test of capacity.

7. Views of People with Intellectual Disability, Families/Others

7.1 To assist with the preparation of this submission to the Oireachtas Committee Inclusion Ireland brought together two focus groups of 12 people each to seek their views on changes to the law. Focus Group 1 consisted of parents of people with intellectual disability, service providers and legal professionals. Group 2 consisted of people with intellectual disability, living in residential settings, at home with their families or independently. Their views are attached to this submission as an Appendix.

8. Conclusion

8.1 The Government has a golden opportunity to make this legislation the best it possible can be. In the last ten years there has been much debate and thought given to this, and while it is extremely important that the Lunacy act of 187 is replaced, it must not be replaced with a system that while being an improvement, is not in line with international best practice, or with the UN Convention on the Rights of Persons with Disabilities.

Appendix

Focus Group1: Tuesday 9th August – participants were family members and professionals

Notes taken – all points below were spoken by focus groups participants and not Inclusion Ireland staff

Ward of Court system:

- Ward of Court system is currently “blanket cover” – it covers all decisions a person makes and not just one area of a person’s life;
- The Ward of Court proceedings “last a long time and benefit nobody”: if money is the issue at stake, then it can preclude access by the person to that money for a long time;
- When a Ward of Court you must ask permission to leave the State;
- When a Ward of Court, the system “is constantly inserting itself into our lives” (spoken by the mother of someone who is a Ward of Court);
- Families are denied access to information on what monies are in the Court funds and are denied access to that money to make arrangements that would benefit the person who is a Ward of Court (i.e. the money the person who is a Ward of Court has);
- While issues were raised about people not being able to access money etc, there was consensus that a system is needed to ensure people are protected also;
- One participant who has worked in the UK for a long time says he is “stunned” at the differences between here and the UK, as we are so far behind the changes made there;
- There was consensus on the right of an individual to not involve their family in decisions they make if they choose not to;
- When you’re a Ward of Court there is no official body you can complain to – you can’t complain to the Financial Regulator or the Ombudsman etc, all avenues are closed off;
- One person made the point that the funds held by their family member who is a Ward of Court halved in the past number of years as they were invested by the Wards of Court system and investment globally went down – point made that having your money in that system does therefore not necessarily protect it;
- A lot of money comes out of the funds held by the Ward of Court system, including monies taken out to run the Ward of Court system. However its difficult to get information on what happens to this money and where it goes;

Focus Group 2: Wednesday 10th August – participants were adults with intellectual disabilities

Notes taken – all points below were spoken by focus groups participants and not Inclusion Ireland staff

- People with intellectual disabilities should have the right to marry, have relationships, make their own medical decisions, work and travel as they decide they want to. They should have the right to supports as they need them;
- If a decision needs to be made about a medical issue, the decision must be down to what the person with a disability wants themselves. The group agreed that some people might need support with this, but it must be the person who makes the decision. If doctors and family members are involved they must ask the person what they want. Also, information must be given properly, explaining what is happening in an accessible way;
- Regarding Disability Allowance and other social welfare payments, if a person doesn't need support in collecting and managing the payment they should be given the choice of doing it themselves. If they need support, it must be someone they trust. This person can be a staff member or family member. The main thing is, it must be the decision of the person themselves, on who collects the payment;
- The group say there are a lot of people with disabilities who are not in control of their money and they can often be afraid of standing up for themselves and saying they want control of their money. Examples were given of people in services having to give back receipts for all the money they spend, and not knowing how much money they have, because other people control it. Examples also given of people asking for money to buy a CD etc and being told they "aren't allowed", despite the fact that the money in question is their own money;
- If people need support in using ATMs etc, they should be supported to learn how to do this;
- If someone can't read, that doesn't give someone else the right to open their bank statements etc without asking, or without telling them they have come. Instead, they must be supported to understand what is in the statements;
- Group say people should be supported to get married, have children and have relationships if they want. A lot of people didn't know that they could be stopped from getting married. The group felt this is a person's right if they choose it;
- It was agreed that the 'Lunacy Act' is very old fashioned and having a law that's 140 years old is ridiculous;

Relevant Publications

- Law Reform Commission *Law and the Elderly*, 2003
 - Inclusion Ireland *Who Decides and How? People with Intellectual Disabilities- Legal Capacity and Decision Making.* 2003
 - Law Reform Commission *Vulnerable Adults and the Law: Capacity.* 2005
 - Law Reform Commission *Report: Vulnerable Adults and the Law* 2006
 - UN Convention on the Rights of Persons with Disabilities 2007
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