



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

**Submission  
to the  
Joint Committee on Justice, Defence and Equality  
on the  
Assisted Decision-Making (Capacity) Bill 2013**

**04 April 2014**

## Introduction

1. Established in 1961, Inclusion Ireland is the national organisation working for the rights of persons with an intellectual disability. Our membership is drawn from persons with intellectual disability; parents and family members; providers of services to persons with a disability, academics, policymakers and others.
2. Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.
3. Persons with an intellectual disability and their families are integral to informing the work of Inclusion Ireland. Following publication of the Assisted Decision-Making (Capacity) Bill 2013 (hereinafter “the Bill”), Inclusion Ireland engaged in a process of consultation with its membership. Consequently, this submission is underpinned by the views and considerations of persons with a disability and their families.
4. This submission builds upon Inclusion Ireland’s presentation to the Joint Oireachtas Committee on Justice, Defence and Equality on 22 February 2012 and to the submissions of the coalition of civil society group on the Bill to the Department of Justice and Equality in November 2013.
5. Inclusion Ireland acknowledges that the Bill provides for an improved statutory framework to assist persons in exercising their decision-making capacity. However, if persons with an intellectual disability are to enjoy legal capacity on an equal basis with others, we believe that the Bill requires some revision.
6. This submission concentrates on the following areas:
  - (A) Statutory Presumption of Capacity;
  - (B) Accessible Information and Awareness Raising;
  - (C) Informal Decision-Making;
  - (D) Assisted Decision-Making
  - (E) Independent Advocacy;
  - (F) Courts and Access to Justice;
  - (G) Office of the Public Guardian;
  - (H) Consent and Capacity in Specific Matters;
  - (I) Existing Wards of Court; and
  - (J) Wills

## **(A) Statutory Presumption Capacity**

7. Inclusion Ireland is disappointed that capacity is defined in the Bill as mental capacity and that a person can be defined as a person who lacks capacity. Thus, the Bill is predicated upon a system where a person's capacity to make important decisions is something that can be tested and, in certain circumstances, removed from a person and given to someone else. This is a medical approach which puts the deficit at the door of the individual rather than a social model that recognises the supports a person needs in order to make a decision
8. Inclusion Ireland recommends that the Bill be predicated upon a definition of legal capacity in accordance with the Article 12 of the UN Convention on the Rights of Persons with Disabilities.
9. Article 12 of the UN Convention on the Rights of Persons with Disabilities places the following legal obligations on States Parties:
  1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
  2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
  3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
  4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
  5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

## **(B) Accessible Information and Awareness Raising**

10. Inclusion Ireland considers the Bill to be an extremely complex piece of legislation that needs to be fully understood by persons with a disability, their family members and advocates.
11. The need for clear, accessible information is a major concern of persons with an intellectual disability, parents and family members consulted by Inclusion Ireland.
12. Inclusion Ireland considers the Bill as a paradigm shift in the way we approach capacity and decision-making. The Bill is about empowering people to exercise their capacity and develop their capacity. There will be a need for training and education and awareness raising about supported decision-making and the provisions of the Act when implemented.
13. Inclusion Ireland welcomes the role of the Office of the Public Guardian (Section 56), in the promotion of public awareness of matters (including the principles and procedures of the UN Convention on the Rights of Persons with Disabilities) relating to the exercising of decision-making capacity by all persons.
14. Inclusion Ireland recommends that Section 56 of the Bill be amended to include a provision that the Office of Public Guardian shall have a function of training and education on the provisions of the Bill. Such a provision would be in keeping with Article 8 of the UN Convention on the Rights of Persons with Disabilities.
15. Inclusion Ireland recommends that the term '*simple language*' in Section 3 (3) is deleted and replaced with 'Plain English'.

## **(C) Informal Decision-making**

16. The system of informal decision-making provided for in Part 7 of the Bill gives legal recognition to a process that is currently most frequently used.
17. Decisions in relation to personal welfare and healthcare can in essence be removed from a person whose capacity is in question and made by others in a loose and unchecked fashion. This constitutes substitute decision-making and opens up a scenario where a person can have decisions relating to his or her life made by others if it is deemed 'necessary'. This effectively enshrines a principle of best interest, which is anathema to a person's right to exercise their legal capacity.
18. Inclusion Ireland considers that the informal decision-making provisions of the Bill offer insufficient safeguards for persons. A person may make an arbitrary decision that another person lacks capacity and is protected in making this assessment. Inclusion Ireland considers this to be *de facto* substitute decision-making.
19. Inclusion Ireland is concerned that Section 53 of the Bill as currently drafted may be in breach of the right to self determination.

20. Inclusion Ireland is further concerned that the informal decision-making provisions of the Bill as currently presented could be used by third parties to make decisions on behalf of persons, rather than using the other decision-making provisions in the Bill.
21. Section 53(3) of the Bill provides that informal decision-makers may be compensated for expenses incurred in the exercise of a decision. Inclusion Ireland considers this an obvious opportunity for financial abuse. It is our view that our any system or process for financial reimbursement must have built in safeguards such as the expense must be necessary, records must be kept and that any informal decision-making involving expenditure must be a one-off and require a report to the Office of the Public Guardian.
22. Inclusion Ireland recommends that Section 53 of the Bill is amended to include provisions that where regular informal decision-making instances are occurring for the same category of decisions, that there is an onus on the informal decision-maker to either seek to be appointed as a co-decision-maker or a personal representative or to ensure that an application is made for another person to assume this role, thereby formalising the arrangement and allowing the relationship to be monitored and reviewed.
23. Inclusion Ireland recommends that Section 53 is amended to include a provision that the provisions in Section 53 should be used only in exceptional circumstances.
24. Inclusion Ireland considers that it is fundamental that the Bill protects persons from unnecessary interference in the exercise of their decision-making rights. The code of practice that is to be developed will be critical in this regard.
25. The Bill is silent about the procedural guidance for communication between an informal decision-maker and the other decision-making mechanisms. If the decision made by an informal decision-maker is to be consistent with other decision-makers, then the communication line must stay open, especially during times of emergency or outside of normal business hours, between the informal decision-maker and the relevant party, to achieve some level of co-ordination and understanding. As it stands, the Bill has not provided for this.
26. Inclusion Ireland recommends that Section 63 of the Bill is amended to include a provision for the preparation by the Office of Public Guardian of A Code of Practice for communication between an informal decision-maker and the other decision-making mechanisms.

#### **(D) Assisted Decision-Making**

27. Section 10(4) of the Bill provides that an appointer (the person whose capacity is in question) may appoint more than one person as a decision-making assistant for different decisions but may not appoint more than one decision-making

assistant in respect of the same decision. Inclusion Ireland is concerned that only one decision-maker is appointed for each decision.

28. In contrast, under Section 23(7) the Court can appoint more than one decision-making representative to act either jointly or jointly and severally. Section 12 of the Bill provides that certain people cannot be appointed a decision-making assistant. However this section is much more limited than the excluded categories of people listed in Section 20 (for co-decision-makers) and Section 24 (for decision-making representatives).
29. Inclusion Ireland recommends that Section 10(4) be amended to allow for at least two assistants to be appointed to assist with the decision.
30. Inclusion Ireland further recommends that Section 12 be amended to include a similar provision to Section 24 that the proposed appointee cannot be the owner or registered provider of a nursing home, a mental health facility, a residential facility or person residing with or an employee or agent of such owner or registered provider.

#### **(E) Independent Advocacy**

31. Inclusion Ireland considers the role of independent advocates in supporting persons with information on the various forms of decision-making to be of fundamental importance. This is an issue that has been consistently raised by members of Inclusion Ireland, particularly by persons with an intellectual disability.
32. Inclusion Ireland considers the system of informal decision-making set out in the Bill as similar to the provisions in the English Mental Capacity Act 2005 where healthcare practitioners are permitted to take certain acts in the best interests of individuals. However, unlike the current Bill, the Mental Capacity Act 2005 has built in a protection in the form of Independent Advocates and this is a safeguard that is not present in the current Bill.
33. Inclusion Ireland strongly believes that independent advocacy can play a key role in facilitating persons to understand the provisions of the Bill and to exercise choice over their decision-making rights. This is particularly the case for persons living in residential care settings.
34. A key provision of the Citizens Information Act, 2007 is the introduction of a Personal Advocacy Service for people with a disability. Under the Act, independent advocates employed by the Personal Advocacy Service would have a range of statutory powers, including the authority to enter residential settings accommodating people with a disability and make enquiries in respect of persons accommodated therein.
35. The failure to establish a Personal Advocacy Service means that vulnerable adults in residential services do not have access to independent advocates with

statutory powers to make inquiries in relation to the persons as the advocate considers appropriate.

36. Inclusion Ireland recommends that the Bill is amended to include provision or the introduction of the Personal Advocacy Service as provided for in the Citizens Information Act, 2007.
37. Inclusion Ireland recommends that Section 3 (2)(d) of the Bill be amended to include 'non-instructed advocacy' as a form of 'any other means'.

## **(F) Courts and Access to Justice**

38. Inclusion Ireland does not consider the Circuit Court to be an appropriate setting for determining a person's decision-making capacity.
39. Inclusion Ireland considers the Bill to be ambiguous as to the question of how (or when) a person can be considered to lose capacity once a decision-making agreement is in place and how the Court should assess capacity in this context. Should an issue arise about a particular decision, does the assessor of capacity, the Judge, then have to consider the person's understanding and communication in the context of the relationship with the assistant who may be a wife, son or carer with personal, intimate knowledge of the appointer? These are exceptionally thorny and difficult issues. Inclusion Ireland is concerned whether these can be adequately dealt with in a busy Circuit Court unless there are special 'permanent' lists where the Judges have specific training and deal with these cases all of the time.
40. Inclusion Ireland considers multi-disciplinary tribunals (for example, the Mental Health Tribunals as provided for in the Mental Health Act 2001) would be more suitable for dealing with applications regarding decision-making capacity than the Circuit Court.
41. Section 23 of the Bill provides for the appointment of a decision-making representative by the Court. Inclusion Ireland is concerned with the absence of any specific provision for consideration of the views and preferences of the person for whom a decision-making representative is being appointed. Under Sections 10 and 18 of the Bill the relevant person chooses the person to be appointed as the decision-making assistant or the co-decision-maker but the Court does not have to seek the views of the relevant person when appointing a decision-making representative.
42. Inclusion Ireland recommends that Section 23 of the Bill is amended to include a provision that the views of the relevant person should be considered.
43. The Guiding Principles provided for in Section 8 of the Bill should also apply to Section 23 and the Court should have regard to the will and preferences of the person and should consider the views of any person engaged in caring for the relevant person, any person who has a *bona fide* interest in the welfare of the relevant person, or a healthcare professional.

44. Inclusion Ireland considers that the views of parents and family members should be regarded by the Court in respect of the appointment of a decision-making representative.
45. Inclusion Ireland recommends that Section 8(8) be amended to make explicit provision for the views of parents, siblings and family members to also be considered.
46. Inclusion Ireland is concerned that the rights to the individual under Article 6 of the European Convention on Human Rights which provides for fair procedure rights to be upheld, the right to be informed of the legal proceedings, the right to be heard, the right to know the evidence being put forward, the right to challenge the decision and furthermore the right to speak and be heard on your own behalf. Article 6 would also provide a right of reasonable legal representation and a right to basic legal assistance and advice.
47. Inclusion Ireland recommends that the Bill be amended to make provision for an automatic right to legal representation, regardless of means, when an application is made to court for a declaration in respect of a person's decision-making capacity. This would be similar to the automatic entitlement to Legal Aid in child abduction cases.
48. Inclusion Ireland further recommends that the Bill include specific provisions to make applications for Legal Aid fully accessible to persons with an intellectual disability.
49. Inclusion Ireland considers it essential that the Bill provides for the availability of independent advocacy support within the court process. The role of an independent advocate can help to ensure equal access and participation of the person. An independent advocate can also support the person with communicating their instructions to the court. To this end, Inclusion Ireland recommends that the Bill makes provisions for the commencement of the Personal Advocacy Service as provided for in the Citizens Information Act 2007.
50. Inclusion Ireland considers that the court should only make findings of incapacity as a last resort to be used for specific decisions and limited timeframes when all decision-making options have been exhausted.
51. Inclusion Ireland recommends the Bill be amended to include a requirement that the court provide written reasons for all of their decisions, and that these reasons be published on an anonymised basis. This would provide transparency for the parents and family members, legal practitioners and civil society organisations.
52. Section 109 of the Bill states that an appeal lies to the High Court from a decision of the Circuit Court or the Supreme Court from the decision of the High Court on a point of law only. Inclusion Ireland considers this to be very restrictive in view of the fact that the decisions to be made by specialist judges on factual issues will be final and no appeal can be taken unless a point of law arises.

53. Inclusion Ireland recommends that the provision in Section 109(a) and 109(b) of the Bill, limiting of appeals to points of law, be deleted from the Bill.

#### **(G) Office of the Public Guardian**

54. The civil society group on legal capacity, of which Inclusion Ireland is a member, recommends that the name of the Office of Public Guardian be amended to the 'Office of Assisted Decision-Making' to better reflect the true purpose of the Bill. Inclusion Ireland strongly endorses this amendment.

55. Inclusion Ireland considers the current ward of court system to be unaccountable and lacking public scrutiny. Parents and family members have reported how they have been excluded from decisions by the Offices of the Ward of Court.

56. Inclusion Ireland welcomes the provisions of Section 56 of the Bill, which require the Office of Public Guardian to disseminate information to members of the public relevant to the performance of its functions to assist members of the public to understand the operation of the Act and role of the Public Guardian.

57. Section 63 of the Bill provides for Codes of Practice that may be prepared and published by the Office of the Public Guardian. Inclusion Ireland recommends that Section 63 is amended to include a Code of Practice on the role of an independent advocate.

58. Inclusion Ireland further recommends that Section 63 of the Bill is amended to include a provision for the involvement of persons with a disability and their representative organisations in the preparation of Codes of Practice.

59. Inclusion Ireland considers that many people who have time and valuable experience of intellectual disability would be willing to act as decision-making assistants on a voluntary basis.

60. Inclusion Ireland recommends that Section 56 of the Bill be amended to include a provision that the Office of Public Guardian maintain a register of volunteers willing to act as assistant decision-makers.

#### **(H) Consent and capacity in specific matters**

61. Section 106 of the Bill retains the law in force concerning capacity or consent required as respects a person in relation to any of the following:

- Marriage
- Civil Partnership
- Judicial Separation
- Divorce
- Dissolution of Civil Partnership
- Placing a child for adoption

- Making of an Adoption Order
- Guardianship
- Sexual Relations
- Voting
- Serving as a member of a jury.

62. Inclusion Ireland considers that the failure of the Bill to address consent and capacity in the aforementioned areas of law effectively abandons persons with an intellectual disability to an ongoing vulnerability and unnecessary restriction of their human rights and fundamental freedoms.

63. Inclusion Ireland strongly recommends that Section 106 of the Bill is amended to include specific clarification stating that the guiding principles and the provisions of Part 3 and Part 4 of the Bill shall apply in these areas.

#### **(I) Existing Wards of Court**

64. Around 100 persons with an intellectual disability are admitted to wardship, annually.

65. Inclusion Ireland is concerned with the provisions of Section 35 of the Bill which deals with the review of capacity of persons currently wards of court. Under the provisions of Section 35 (2) wards of court may have to wait up to three years to be discharged from wardship. Inclusion Ireland considers this unacceptable.

66. Inclusion Ireland recommends that Section 35(2) of the Bill is amended to provide for the all persons currently wards of court have access to the decision-making provisions of the Bill immediately.

#### **(J) Wills**

67. Inclusion Ireland recommends that Section 108 of the Bill makes clear that the Guiding Principles (Section 8) and the provisions of Parts 3 and 4 of the Bill equally apply where someone wishes to make a will and that Section 108 (1) be amended accordingly.