# Global to Local – Convention on the Rights of Persons with Disabilities to the Assisted Decision Making Bill

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# Today let's talk about...

- Decision Making
- Convention on the Rights of People with Disabilities
- Committee of the UN Convention on the Rights of People with Disability
- Assisted Decision Making Bill
- Guiding Principles
- Decision Making Framework
- Where are we now?
- Questions?

# What decisions do you make?

• What decisions have you made today?





• Did you need support to make some decisions?

• Who did you choose to support you?

### What is Capacity to make decisions?

Discussion



#### **United Nations**

**Charter in 1945** 

Formed at the end of world war two

194 countries in the world part of the United Nations



# Universal Declaration – Eleanor Roosevelt



"Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerned citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

#### **Universal Declaration of Human Rights (1948)**

# International Covenant on Civil and Political Rights (ICCPR) (1966)

International Covenant on Economic, Social and Cultural Rights
(ICESCR) (1966)

# Convention on the Rights of Persons with Disabilities



#### Convention

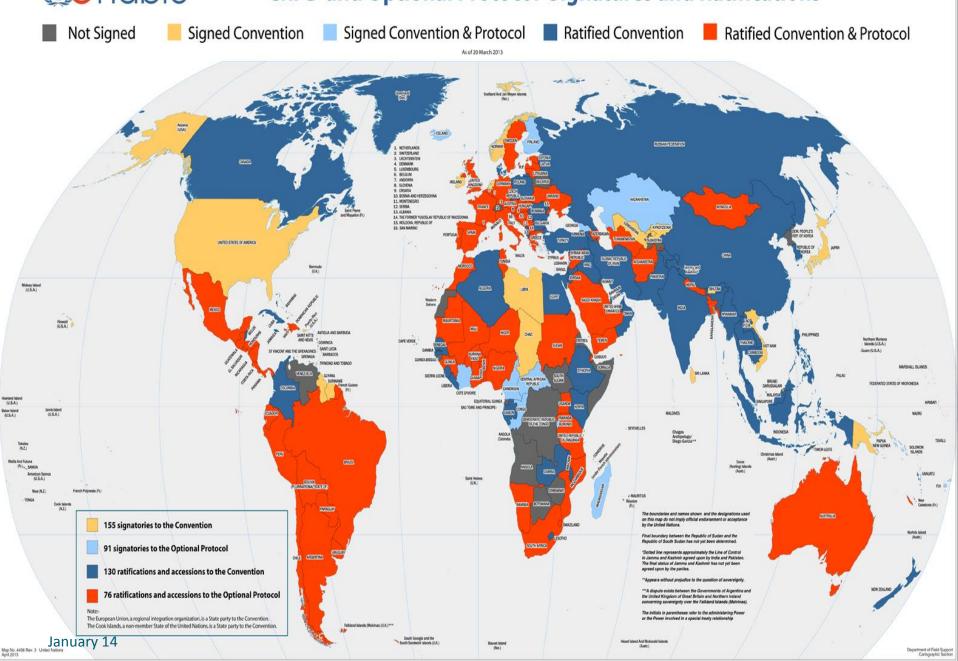
- 158 signatures
- 141 ratifications

#### **Optional protocol**

- 92 signatures
- 79 ratifications



#### **CRPD and Optional Protocol Signatures and Ratifications**





# International Disability Caucus

- People with all kinds of disabilities from all around the world
- People with intellectual disability and people with mental health difficulty worked together
- Advocates supported by Inclusion International made important statements about being heard - about closing institutions and about making decisions.

• Robert Martin – II



# Amita Dhanda addressing the Adhoc Committee on behalf of IDC:

#### Paternalism has never protected

"It has not been recognised that disability has been long equated with incompetence. This equation has not just been confined to social prejudice but has passed into law."

## Article 3 – General Principles

- Dignity and Autonomy
- Non discrimination
- Freedom to make ones own choices,
- Independence of others
- Participation and inclusion
- Accessibility
- Equal opportunity
- Respect for difference



# Past - before the CRPD

**Substitute Decision Making** 

Non
Person

Supported Decision Making

Person

#### Article 12.

Being treated equally by the law.

Article 12 is key to Ireland ratifying the Convention



# Making Decisions about ourselves or everyone





# Article 12 –Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

From the moment you are born

#### Article 12 Equal recognition before the law

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Capacity to act – vote, relationships, marriage, buy a house. "Open up possibilities and fends off unwarranted intrusions into the person's life."

#### **Supported Decision Making**

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.

Assisted /Technical Support Circle of supports, Community of interpretation Capacity of the decision

## Safeguards

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.

## Property and Financial Affairs

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.

# Control money

#### **Equal right to**

- \*Inherit property
- \*Control financial affairs
- \*Bank loans, mortgages
- \*Not deprived of their property



### Article 12

- Disabled people are to be respected as people like everyone else.
- As citizens
- In contracts
- Supported decision making
- Will and preferences



# Paradigm Shift Vision - Reframing Radical View of Personhood and Article 12

- Elements of Personhood Dignity
- Dispel Legal Fiction of Rationality
  - Directed by Will and Preferences ascribed by at least one person –
     Community of interpretation Not best interests principle
  - Irrational choices are reality defines who we are!
  - Right to make bad decisions Dignity of Risk
  - Shift from cognitive tests and functional tests?
  - Family and friends support in decision making
  - Contracts house, marriage, BANKS!
  - Prevent enforced treatment
- Bulldozes away barriers to personhood

### Guardianship - not a panacea?

#### Countries that have had guardianship argue that:

- Avoid legal declaration of not being equal before the law
- PROMOTE independence, dignity Freedom of choice
- Put PERSON first not guardian
- Expense legal representation
- Experience before courts negative
- Hard to remove
- Corporate Guardians –

It doesn't do what it says on the tin – does not protect persons rights

**ARC Michigan** 

United Nations Committee on the Convention on the Rights of Persons with Disabilities

Once Ireland Ratifies the Convention on the Rights of Persons with Disabilities

- State Report
- Go before the UN Committee on the Convention on the Rights of Persons with Disabilities



## **Concluding Observations**

 "[The State Party must] review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences"

UN Committee on the Rights of Persons with Disabilities (Tunisia, Spain, Peru, Argentina, China, Hungary, Paraguay, Austria, Australia, El Salvador)

#### **Draft General Comment**

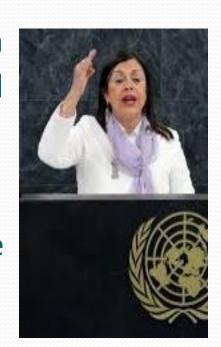
Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency).

Article 12 does not permit perceived or actual deficits in mental capacity to be used as justification for denying legal capacity, even in respect of a single decision.

Functional tests of mental capacity that lead to denials of legal capacity violate Article 12 if they are either discriminatory or disproportionately affect the right of persons with disabilities to equality before the law.

# Substitute Decision-Making

- 1. Legal capacity is removed from the individual, even if this is just in respect of a single decision
- 2. A substituted decision-maker can be appointed by someone other than the individual, and this can be done against the person's will
- 3. Any decision made by a substitute decision-maker is bound by what is believed to be in the objective 'best interests' of the individual as opposed to the individual's own will and preferences.



# Supported Decision-Making

A broad term which covers informal and formal support, and arrangements of varying type and intensity, e.g.:

- Choosing one or more trusted supporters to assist in exercise of legal capacity for various types of decisions.
- Peer support, advocacy (including self advocacy support), or assistance in communication.
- Universal design and accessibility, e.g. third parties providing understandable information such as banks and financial institutions
- Development and recognition of diverse and unconventional methods of communication, especially for those who use non-verbal communication to express their will and preferences.

## **Supports MUST:**

- Be available to all, regardless of level of support needs/'naturally occurring' support
- Safeguards based on will and preferences
- Communication or lack of financial resources must not be a barrier to accessing support
- Supporters chosen must be legally recognised
- Never used to limit other fundamental rights
- Person can refuse, change or end
   January propert



# Coalition for Progressive Legal Capacity Legislation

# Coalition for progressive Legal Capacity legislation

- Started meeting in Summer 2011
- Guiding Principles
- Number of events
  - Dublin
  - Attended Consultation Meeting in October
- Equality Dignity and Human Rights
- Submission October 2014
- Textual amendments

# IRN Attend Consultation Symposium



### The Assisted Decision-Making (Capacity) Bill 2013:

What Does It Mean?

#### New Law is proposed

Assisted Decision
 Making (Capacity)
 Bill 2013

• Bill = Draft = not final



#### But first...

- This law is only for people over 18
- It is still a Bill so it may be changed before it becomes law
- It does NOT change many other laws including laws about voting, marriage, mental health treatment and consent to sex
- Many parts of the law are still unclear and will need a Code of Practice to explain them

#### What is Capacity to make decisions?

- Understand information
- Remember it
- Use or weigh it
- Communicate it

Applies to EVERYONE –
not just people with a
disability or diagnosis



#### Capacity to make decisions

Part 1 Section 3 cont

2 (d) cont. (whether by talking, writing, using sign language, assisted technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.

#### Accessible information

• (3) A person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (whether using simple language, visual aids or any other means).

(4) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him or her from being regarded as having the capacity to make the decision.

#### Accessible Information.

• It includes the provision for the accessible provision of information.

What might this include?



#### Capacity to make decisions

- (5) For the purposes of this section, information relevant to a decision shall be construed as including information about the reasonably foreseeable consequences of—
- (a) each of the available choices at the time the decision is made, or
- (b) failing to make the decision.
- (6) Any question as to whether a person lacks capacity shall be decided on the balance of probabilities.

#### Courts vs Tribunals

- 4.—(1) .. the performance of the functions of that court conferred .. within the jurisdiction of the **Circuit Court** 
  - (a) the relevant person the subject of an application under this Act is residing or carrying on business at the time the application is made, or
  - (b) the relevant person the subject of an application under this Act has resided at any time during the period of 3 years immediately prior to the making of the application.
- (2) .. the High Court, and not the court, shall have jurisdiction relating to every matter in connection with—
  - (a) non-therapeutic sterilisation,
  - (b) withdrawal of artificial life-sustaining treatment, or
  - (c) the donation of an organ,

where the matter concerns a relevant person who lacks capacity.

#### Functional test of capacity

Chapter 3: Declarations as to capacity, etc., and matters following declarations

• 15.—(1) Subject to subsection (2), the court, on application to it by a person entitled by virtue of section 14 to make the application, may make one or both of the following declarations:



...

#### Part 2 – 8. Guiding Principles

**Assisted Decision Making Bill** 

#### Principles

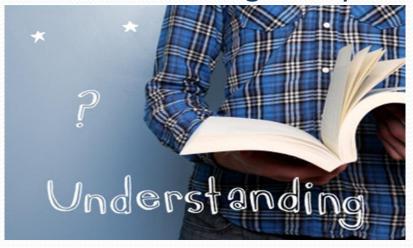
- Presumption of capacity
- Accessible information
- Allowed to make 'unwise' decision
- Intervention must be necessary and least restrictive of your freedom, rights and dignity
- Person must participate in intervention
- Will and preferences (as far as practicable)
- Talk to others who know the person well



#### Presumption of capacity

Part 2 - 8.(2)

- Presumption of capacity
- Assumes everyone has decision making ability



8(3) A relevant person who falls within paragraph (a) of the definition of "relevant person" in section 2(1) shall not be considered as unable to make a decision in respect of the matter concerned unless all practicable steps have been taken, without success, to help him or her to do so.

## Recognises right to make 'unwise' decision.(4)

(4) A relevant person who falls within paragraph (a) of the definition of "relevant person" in section 2(1) shall not be considered as unable to make a decision in respect of the matter concerned merely by reason of making, having made, or being likely to make, an



January 14 wise decision.

#### Least restrictive on rights and

#### freedoms (5,6)

- (5) There shall be no intervention in respect of a relevant person unless it is necessary to do so having regard to the individual circumstances of the relevant person.
- (6) An intervention in respect of a relevant person shall—(a) be made in a manner that minimises
- (i) the restriction of the relevant person's rights, and
- (ii) the restriction of the relevant person's freedom of action, and
- (b) have due regard to the need to respect the right of the relevant person to his or her dignity, bodily Integrity, privacy and autonomy.



- (7) The intervener, in making an intervention in respect of a relevant person, shall
  - (a) permit, encourage and facilitate, in so far as is practicable, the relevant person to participate, or to improve his or her ability to participate, as fully as possible, in the intervention,
- (b) give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable,

#### (c) take into account—

- (i) the beliefs and values of the relevant person (in particular those expressed in writing), in so far as those beliefs and values are reasonably ascertainable, and
- (ii) any other factors which the relevant person would be likely to consider if he or she were able to do so, in so far as those other factors are reasonably ascertainable,

- (d) Unless .. not appropriate or practicable to do so, consider the views of
- (i) any person named by the relevant person as a person to be consulted on the matter concerned or any similar matter, and
- (ii) any decision-making assistant, co-decision-maker, decision-making representative or attorney for the relevant person, and

#### Principles 8 (7 e)

- (e) consider all other circumstances of which he or she is aware and which it would be reasonable to regard as relevant.
- Normative context

 Needs strengthened re reasonable provision

#### How are decisions made?

Will and Preferences

**Best interests** 





- (8) The intervener, in making an intervention in respect of a relevant person, may consider the views of
- (a) any person engaged in caring for the relevant person,
- (b) any person who has a bona fide interest in the welfare of the relevant person, or
- (c) healthcare professionals.

Family members are not mentioned specifically in the list of who to consult in relation to decisions, but reference is made to "any person engaged in caring for the relevant person."

#### To understand the person

 Talk to others who know the person well

Who would we choose?



### (9) In the case of an intervention in respect of a relevant person who lacks capacity, regard shall be had to

 (a) the likelihood of the recovery of the relevant person's capacity in respect of the matter concerned, and  Gives opportunity to delay decisions until a better time.

 (b) the urgency of making the intervention prior to such recovery.

#### Decision Making Framework

Assisted Decision Making Bill

# The ADM Bill introduces a legal framework for:

- Informal Decision Making,
- Assisted Decision Making and decision making assistance agreements,
- Co Decision Making, and
- Decisions by Court or Decision Making Representative and order (Guardianship but must respect will and preferences).



the decided	The second secon	
the decision?	When?	What kind of decision?
n assistant, if	You have capacity to make that decision?	Any decision – about personal welfare or financial issues
Decision-	You wouldn't have capacity on your own to make the decision	Any decision – about personal welfare or financial issues
	You don't have capacity on your own to make that decision and don't have a co decision-maker	Any decision – about personal welfare or financial issues
has a power of	You give the person the power to act for you before you lose capacity	Any decision – about personal welfare or financial issues
cision-maker	They believe you lack capacity to make decision?	Personal welfare decision ONLY
gh Court	You don't have capacity on your own, and it is urgent or an emergency	Circuit court unless organ donation, end of life or sterilisation - High Court
	n assistant, if  Decision-  king ive  has a power of  cision-maker  gh Court	Decision- You wouldn't have capacity on your own to make the decision  You don't have capacity on your own to make that decision and don't have a co decision-maker  Has a power of You give the person the power to act for you before you lose capacity  They believe you lack capacity to make decision?  You don't have capacity on your own, and it is urgent

#### Part 3 – Assisted Decision Making

Part 3, 9. Assisted Decision Making Bill

#### Assistance Agreements (1)

- Anyone can make this kind of agreement once they are over 18
- The law says you must think your capacity is 'in question or shortly may be in question' for the agreement to be used
- If someone else challenges your decision you can show them your agreement

#### Assistance Agreements (2)

#### You

 Choose someone you trust (car be more than one)

 Make an agreement, saying what decisions you want he with and who will help

Give notice to Public Guardian

Change it if you want

#### **Your Assistant**

Advises you about the decision

Helps you to communicate your decision and makes sure your wishes are followed

Can access some documents about you needed for the decision

 Does NOT make the decision for you

#### Assisted Decision Making

- 10.—(1) Subject to section 12, a person who has attained the age of 18 years and who considers that his or her capacity is in question or may shortly be in question may appoint another person who has also attained that age to assist the first-mentioned person in making one or more than one decision on the firstmentioned person's personal welfare or property and affairs, or both, in compliance with regulations made under subsection (3).
  - Decision Making Assistant Agreement
  - Regulations for agreements:
    - Form of DM Agreements
    - Procedures for DMA
    - Prescribing information for DMA
    - Understanding of agreement and obligations
    - Personal welfare or property and affairs or both
    - Inform public guardian
    - One person one decision

#### The functions of a decisionmaking assistant to an appointer:

- (a) to advise by explaining relevant information and considerations relating to a relevant decision,
- (b) to ascertain the will and preferences on a matter the subject of a relevant decision and to assist the appointer to communicate them,
- (c) to assist in obtaining any information or personal records that the appointer is entitled to and is required in relation to a relevant decision,
- (d) to assist the appointer to make and express a relevant decision, and
- (e) to endeavour to ensure that the appointer's relevant decisions are implemented.

# Part 7 – Informal Decision Making

Assisted Decision Making Bill

#### Informal Decision-Making

- Allows someone to make a decision as if you had capacity and authorised them to make it
- Must comply with general principles
- ONLY for personal welfare matters
- Paid for expenses from you money
- Still liable for criminal or civil negligence

Must not make a decision that goes against assistant, co decision, or epresentative

Can't make a decision that only the High Court can make

If waiting for a court decision, can continue to provide life sustaining treatment or prevent deterioration of health

Few safeguards

#### Informal Decision making Part 7

53.—(1) Subject to section 54, notwithstanding that a person (in this section and section 53 referred to as an "informal decision-maker") is not a decision-making assistant, codecision-maker, decision-making representative or attorney for a relevant person, the informal decision-maker may take or authorise the taking of an action in respect of the personal welfare (including healthcare and treatment) of the relevant person where the provisions of this section are complied with and the action is neither a matter referred to in section 4(2) nor a matter closely connected with a matter referred to in section 4(2).

#### Informal DM cont:

- (2) An informal decision-maker who, in taking or authorising the taking of an action in respect of a relevant person, acts in compliance with the provisions of this Act shall not incur any legal liability which he or she would not have incurred if the relevant person—
- (a) had the capacity to consent in relation to the action, and
- (b) had given consent to the informal decision-maker to take or authorise the taking of the action.

## Part 4 – Co- Decision Decision Making

Part 4, Chapter 4 Assisted Decision Making Bill

#### Co Decision-Making Agreements (1)

- You can make this kind of agreement on your own once you are over 18 and consider that your capacity 'is or shortly may be in question'
- Even if you don't make this agreement, someone can apply to court to say you lack capacity without a codecision-maker and the court will decide if you need one, but you must agree to this

### Co Decision-Making Agreements (2)

#### You

**Co Decision-Maker** 

 Make an agreement with someone you trust (can be more than one)

 Say which decisions you will make TOGETHER

 Court can approve your agreement or say that you should have one – but cannot give you a co decision-maker unless you AGREE  Advises you about the decision and makes the decision WITH you

Writes a report once a year to the Public uardian

 MUST agree with the decision you make unless it is unreasonable or likely to cause harm

## Co- Decision Decision Making

- Choose appointer
- Subject to Co Decision Order to have legal effect
- (2) A person is suitable for appointment as a co-decision-maker for another person if— (a) the first-mentioned person is a relative or friend of the proposed appointer who has had such personal contact with the proposed appointer over such period of time that a relationship of trust exists between them, and (b) the first-mentioned person is capable of effectively performing the functions which it is proposed to give to the co-decision-maker for the proposed appointer. 25
- (3) An appointment as a co-decision-maker shall be made in a co-decision-making agreement which is in compliance with regulations made under subsection (4).
- (4) The Minister may make regulations as respects co-decision making agreements, including—prescribe form, procedures, and information
- One person one decision
- Personal welfare or property

#### Exclusion of appointee under CoDM

- 20.—(1) Subject to subsection (3), a person (in this subsection referred to as the "proposed appointee") shall not be appointed as a co-decision-maker if—
- (g) the proposed appointee is the owner, or the registered provider, of a nursing home (whether or not it is a nursing home registered under the Health Act 2007), a mental health facility, or a residential facility for persons with disabilities, in which the relevant person resides, or a person residing with, or an employee or agent of, such owner or registered provider, as the case may be, unless the proposed appointee is a spouse or civil partner, parent, child or sibling of the relevant person.

## Co Decision Making

- 21.—(1) Subject to section 17(3), a co-decision-maker for the appointer shall advise the appointer respecting matters the subject or to be the subject of relevant decisions, and shall share with the appointer the authority to make relevant decisions and may do all things necessary to give effect to the authority vested in him or her.
- Co sign documents
- (7) (a) A co-decision-maker for the appointer shall, at least once every 12 months after the co-decision-making agreement which appointed the co-decision-maker becomes the subject of a codecision-making order, or within such shorter period as the court may direct, prepare and submit to the Public Guardian a report in writing as to the performance of his or her functions as such codecision-maker.
- Limits on property and gifts

## Obligation to Acquiesce

- 19.—A co-decision-maker for the appointer shall acquiesce in a relevant decision made by the appointer and shall not refuse to sign a document referred to in section 21(2) if the following 2 conditions are met:
- (a) a reasonable person could have made that relevant decision; and
- (b) no harm to the appointer or any other person is likely to result from that relevant decision.

## Part 4 – Application to Court

Part 4, Assisted Decision Making Bill

## Application to Court

- (4) An application to the court under this Part (including an ex parte application under subsection (2)) shall state:
- (a) the applicant's connection with the relevant person,
- (b) the benefit to the relevant person sought to be achieved by the application, and
- (c) the reasons why the application is being made, in particular—
- (i) the reason why the benefit to the relevant person sought to be achieved has failed to be achieved in any other appropriate and practicable manner taken prior to the making of the application, and
- (ii) the reason why, in the opinion of the applicant, no other appropriate and practicable manner to achieve that benefit remains to be taken prior to the making of the application.

## **Expert Reports**

- 30.—(1) In considering any application under this Part for a declaration, order or review, the court shall have all such powers as are necessary to assist it in making a decision.
- (2) For the purposes of an application referred to in subsection
- (1), the court may direct that such reports as the court considers necessary be furnished to it, including—
- (a) medical reports relating to the relevant person the subject of the application (including reports relating to the cognitive ability of that person),
- (b)reports relating to the circumstances of the relevant person (including financial reports and valuations of property in which the relevant person has an interest), and
- (c) reports from healthcare professionals relating to the relevant person.

#### **Court Friend**

- 60. (2) (a) A court friend for a relevant person is a person who assists the relevant person in relation to an application under Part 4 in respect of which the relevant person is the subject.
- (b) The court, on the hearing of such application, may hear submissions from the court friend on behalf of the relevant person.
- Access to information 1 §

- Court Friend New Term similar to Guardian Ad Litem for Children – appointed when process underway
- Declaration of Incapacity by Court Part 4, Chapter 3
- Welfare includes any health care decision, MH treatments, restraint, sexual relationships, contact and where the person lives.

# Decision-Making Representatives

### Decision-Making Representatives (1)

- Someone has to apply to court to say you should have a decision-making representative.
- Court will decide to give you a representative if you don't have the capacity to make a decision on your own, but you would with a co decision-maker (but none is available), or you would not have the capacity even with a co decision-maker

### Decision-Making Representative (2)

#### You

 Someone applies to court (ca be you or someone else)

 Court will decide if you have capacity and if not will appoin a representative

 Court will say what decisions the representative can make

#### **Your Representative**

Can be someone you know or someone from a panel by the Public Guardian (court decides)

Can be more than one person for each decision

 Reports to Public Guardian once a year and can be paid for expenses out of your money

# Decisions by Court or Decision Making Representatives Chapter 5

- Declaration re capacity to make decisions
- CH 5 (2) Where this section applies, the court may make one or both of the following orders: (a) an order making the decision or decisions concerned on behalf of the relevant person where it is satisfied that the matter is urgent or that it is otherwise expedient for it to do so;
- (3) Where the court proposes to appoint a decision-making representative for a relevant person but no suitable person is willing or able to act as such decision-making representative— (a) the court shall request the Public Guardian to nominate 2 or more persons from the panel established under section 61(1) for consideration by the court for such appointment, and
- (b) the court may, under subsection (2)(b), appoint, from amongst those nominees, a person to be a decision-making representative for the relevant person for the purposes referred to in that paragraph.

## Decision-making representative

- (10) Where the court is satisfied that a decision-making representative for a relevant person has behaved, is behaving or is proposing to behave in a manner outside the scope of the authority conferred on him or her by the court, or in a manner that is not in the interests of the relevant person, the court may
- (a) revoke the appointment of the decision-making representative, or (b) vary the terms of a decision-making representative order relating to— (i) the appointment of the decision-making representative, (ii) the nature or extent of the powers conferred on the decision-making representative, or
- (iii) the duties imposed on the decision-making representative.
- Not a Service Provider
- Annual report to Public Guardian

# Scope of (guardianship) Welfare

#### **Decisions**

- 25.—Subject to section 27, a decision-making order or decision-making representative order, as appropriate, relating to the personal welfare of a relevant person—
- (a) may, without prejudice to the generality of section 23(2)(b), authorise a decision-making representative for the relevant person to make decisions on behalf of the relevant person in respect of any one or more than one of the following matters: (i) where the relevant person should live; (ii) persons with whom the relevant person may or may not have contact; (iii) the employment, training and rehabilitation the relevant person should receive; (iv) the diet and dress of the relevant person; (v) the inspection of the personal papers, or a class of personal papers, of the relevant person; (vi) whether or not the relevant person may travel outside the State; (vii) granting or refusing consent to the carrying out or continuation of a treatment of the relevant person by a healthcare professional; and
- (b) may make provision for such other matters as the court considers appropriate.

# Scope of (guardianship) decision making re property and affairs

- (i) the custody, control and management of some or all of the relevant person's property or property rights;
- (ii) the sale, exchange, mortgaging, charging, gift or other disposition of the relevant person's property;
- (iii) the acquisition of property in the name of the relevant person, or on his or her behalf;
- (iv) the carrying on, on behalf of the relevant person, of any profession, trade or business which may lawfully be carried on by a person other than the relevant person;
- (v) the making of a decision which will have the effect of dissolving a partnership in which the relevant person is a partner;
- (vi) the carrying out of any contract entered into by the relevant person;
- (vii) the discharge of the relevant person's debts or other obligations, whether or not any such debt or obligation is legally enforceable against the relevant person;

## Not a service provider

• 24 (g) the proposed appointee is the owner, or the registered provider, of a nursing home (whether or not it is a nursing home registered under the Health Act 2007), a mental health facility, or a residential facility for persons with disabilities, in which the relevant person resides, or a person residing with, or an employee or agent of, such owner or registered provider, as the case may be, unless the proposed appointee is a spouse or civil partner, parent, child or sibling of the relevant person.

#### Cont:

- (viii) the execution or exercise of any of the powers or discretions vested in the relevant person as a tenant for life;
- (ix) providing, to the extent that the relevant person might have been expected to do so, for the needs of the decision-making representative or of other persons;
- (x) the conduct of proceedings before any court or tribunal, whether in the name of the relevant person or on his or her behalf;
- (xi) making an application for housing, social welfare or other benefits or otherwise protecting or advancing the interests of the relevant person in relation to those matters, and
- (b) may make provision for such other matters as the court considers appropriate.

# Powers of Attorney

## Powers of Attorney (1)

 You make a 'power of attorney' once you are over 18. It is an agreement that someone you choose will make decision(s) for you once you consider that your capacity is or shortly may be in question.

• This replaces the Enduring Powers of Attorney Act 1996. If you appointed an attorney under the old law, it still applies. Otherwise, this new law applies

## Powers of Attorney (2)

#### You

 Choose someone you trust (can be more than one)

 Make a power of attorney (need doctor to say you have capacity to make one)

 Say which decisions you want to be made for you and who should make them

#### **Your Attorney**

Registers your agreement with the Public Guardian (giving notice to others who can object)

Makes a report once a year to the Public Guardian

Makes decisions FOR you in the areas you agreed on

# **Support Structures**

#### Office of Public Guardian

- Raise awareness about UN Convention & Act
- Supervise assistants, co decision-makers, representatives and attorneys
- Appoint panels of representatives, court friends, special and general visitors
- Keep a register of agreements, read reports
- Deal with complaints and start investigations
- Give advice to the court making a decision



## Special visitors and General Visitors

- (2) A special visitor—
- (a) is a registered medical practitioner who has particular knowledge, expertise and experience as respects the capacity of persons, or
- (b) is a person who, although not a registered medical practitioner, is, in the opinion of the Public Guardian, a person who has particular knowledge, expertise and experience as respects the capacity of persons.
- (3) A general visitor is a person who, in the opinion of the Public Guardian, is a person who possesses relevant qualifications, or has other relevant expertise or experience, to assist the Public Guardian in performing his or her supervisory function referred to in section 56(2)(a).

#### Restraint

- (5) A decision-making representative for a relevant person shall not do an act that is intended to restrain the relevant person unless—
- (a) the relevant person lacks capacity in relation to the matter in question or the decision-making representative reasonably believes that the relevant person lacks such capacity,
- (b) the decision-making representative reasonably believes that it is necessary to do the act in order to prevent harm to the relevant person or to another person, and
- (c) the act is a proportionate response to the likelihood of the harm referred to in paragraph (b) and to the seriousness of such harm.

#### Restraint cont

- (6) For the purposes of this section, a decision-making representative for a relevant person restrains the relevant person if he or she—
- (a) uses, or indicates an intention to use, force to secure the doing of an act which the relevant person resists,
- (b) restricts the relevant person's liberty of movement, whether or not the relevant person resists, or
- (c) authorises another person to do any of the things referred to in paragraph (a) or (b).
- (7) For the purposes of this section, a decision-making representative for a relevant person does more than restrain the relevant person if he or she deprives the relevant person of the relevant person's liberty within the meaning of Article 5(1) of the European Convention on Human Rights.

#### Detention Part 9

- Circuit Court or High court
- Psychiatrist re mental disorder
- Approved Centres
- Wardship reviews



#### Wards of Court

- Everyone who was a ward before the Act will be reviewed within 3 years but can apply to court for review as soon as the Act is passed
- Everyone who was a ward will be discharged eventually, and a different order will be made (e.g. co decisionmaking or representative) but the court will decide when this will happen and will base this on the person's capacity

## Right to Intimate Relationhsips

 The Bill does not address the issues raised by the Criminal (Sexual Offences)
 Act 1993 on the rights of people with intellectual disability



## Advocacy

 There is little reference to an expanded role for Advocacy



 Parts of the law are still unclear and will need a Code of Practice to explain them.



### Questions

- Safeguards in informal decision making?
- Other safeguards freedom from conflict of interest?
- Can support staff be in role of decision making assistants?
- Who and how will informal and assisted decision making be monitored?
- Limits on restraint limited definition psycho tropic medication?
- Legal Capacity (Rights of Adults) vs Mental Capacity =
   Decision Making ability

## How Does the Bill Compare?

- Retains assessments of mental capacity and substitute decision-making
- But says decisions should be based on will and preferences 'as far as practicable'
- Nothing for those who don't have natural support
- 'Best interests' v 'interests'?
- Doesn't cover 'all aspects of life' mental health, consent extends, marriage, voting, jury service, etc.

## What have civil society said?

- Expand assisted decision-making
- More choice and control in deciding who will assist in making decisions
- Informal decision-making is really problematic
- People need real ability to challenge decisions (e.g. advocacy, legal aid and costs)
- Bill needs to interact with Mental Health Act and other relevant laws
- Safeguards needed for those de facto detained
- Strong review clause and rename OPG

# What have other countries done?

- British Columbia, Representation Agreements: low threshold, relationship of trust
- Sweden, Personal Ombuds: for those with no naturallyoccurring support
- India, Draft Rights of Persons with Disabilities Bill: recognises right to legal capacity
- Newfoundland & Labrador Model Legislation: legally independent, supported, represented, facilitated

#### Resources

#### **Irish Bill**

- Explanatory Memorandum of Bill
- <u>Civil society response</u>
- Blog posts: <u>Human Rights in</u>
   <u>Ireland</u>, <u>The Small Places</u>,
   <u>Darius Whelan</u>, <u>Mary</u>
   <u>Donnelly</u>

#### **International sources**

- UN Committee <u>Concluding</u>
   <u>Observations</u>, <u>Draft General</u>
   <u>Comment</u>
- Indian Bill, PO Skane, BC Representation Agreement Act and Guidance (NIDUS)

#### Resources

- Human Rights Yes <u>www.hrusa.org</u>
- Harvard Disability project <u>www.hpod.org</u>
- Disabled Persons International <u>www.dpi.org</u>
- RatifyNow www.ratifynow.org
- Easy to read versions www.fedvol.ie/ fileupload/File/UN%20Convention%20for%20Persons
- Children's version www.unicef.org
- UN www.un.org/disabilities
- International Disability Alliance www.internaionaldisabilityalliance.org
- Office of High Commissioner Human Rights www.unhchr.org
- Inclusion international <u>www.inclusion-international.org</u>
- Inclusion Europe <u>www.inclusion-europe.org</u>