

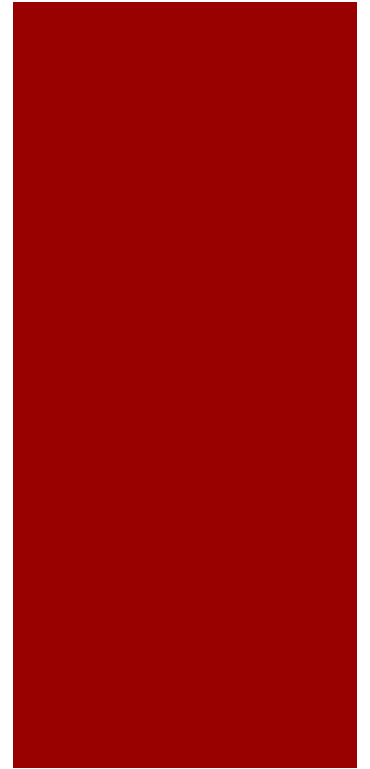
'Implementing the CRPD in Ireland: Legal Capacity, Access to Justice and Disability Law and Policy'

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Overview of Presentation



1. Disability Law & Policy in Ireland
2. Legal Capacity Law Reform in Ireland



Part 1: Disability Law & Policy in Ireland

Strategy for Equality (1996)



- The Report of the Commission on the Status of People with Disabilities – entitled A Strategy for Equality (1996).
- The Strategy for Equality was a watershed with regards to the rights of persons with disabilities in Ireland

Strategy for Equality (1996)

- The Report of the Commission on the Status of People with Disabilities – entitled **A Strategy for Equality** (1996).
- Established by Minister for Equality and Law Reform Mervyn Taylor in 1993.
- The Report signaled the need to adopt a more rights based approach to disability in light of international trends such as the introduction of the Americans with Disabilities Act 1990.
- Major consultative process involving persons with disabilities – who expressed frustration in relation to their exclusion – 600 written submissions received – 327 from persons with disabilities – 111 from parents and friends of persons with disabilities – 162 from organisations. In addition to 30 well attended listening meetings.



Strategy for Equality (1996)



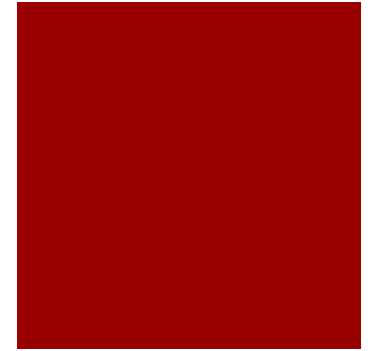
- The Commission's Report was endorsed by all political parties.
- It was also widely supported by all sectors of society.
- It contained **402** recommendations

Recommendations under the following headings:

- The Legal Status of Persons with Disabilities
- Policy Development & Implementation
- Delivering the Necessary Services

Scope of the Strategy for Equality (1996)

- Income & Disability
- Work & Training
- Insurance
- Access
- Health
- Education
- Housing & Accommodation



Scope of the Strategy for Equality (1996)

- Transport & Mobility
- Technology & Communications
- The Law & the Legal System
- Political Rights
- The Inclusion of Women with Disabilities
- Sexuality & Relationships
- Religious Practice
- Arts & Culture
- Media
- Sports Leisure & Recreation
- Vulnerable People with Disabilities
- Research



Strategy for Equality (1996)



■ Key Recommendations:

- ✓ Creation of the **National Disability Authority** (NDA)
- ✓ **Definitions** of **disability** should use language that **reflects** the **rights** of persons with disabilities to be treated as full citizens
- ✓ Enactment of a **Disability Act**
- ✓ A **comprehensive strategy** on disability that changed the relationship between service providers and persons with disabilities to reflect partnership
- ✓ Review of the law on **legal capacity**
- ✓ Inclusion of the disability ground in **employment equality law**
- ✓ No person should be overlooked for medical **treatment** or have treatment delayed or curtailed because of a disability

Strategy for Equality (1996): Implementation?



- An internal progress Review of the Report carried out an inter-departmental task force in 1999.
- It reported that 20% of the Report's recommendations were implemented fully.
- Progress had been made on 66% of the recommendations.
- There was no consultation with members of the disability community in relation to the their perceptions of progress.

Irish Equality Legislation

- **Employment Equality Act 1998 (as amended)**
- **Equal Status Act 2000 (as amended)**



The Arrival of Equality Legislation



- The Equality Authority is an independent body established under the Employment Equality Act 1998.
- The Equality Authority replaced the Employment Equality Agency, and has a greatly expanded role and functions.
- The Equality Authority was merged in 2014 into the Irish Human Rights & Equality Commission.

The National Disability Authority (NDA)

- The National Disability Authority is the independent statutory body that provides information and advice to the Government on policy and practice relating to persons with disabilities.
- Assist the Minister for Justice and Equality in the co-ordination of disability policy.
- Funded by government.

The logo for the National Disability Authority (NDA) features the letters 'n', 'D', and 'A' in a stylized, rounded font. The 'n' and 'A' are colored in a vibrant magenta, while the 'D' is black. The letters are positioned horizontally and are of similar height.

Údarás Náisiúnta Míchumais
National Disability Authority

National Disability Strategy (2004)

- The Government established the National Disability Strategy on 21/09/, 2004 to underpin the participation of people with disabilities in Irish society.
- The rationale for the NDS? To achieve a joined-up approach across key Government Departments
- Main aspects of the NDS?
- Core elements:
 - Legislation (Disability specific legislation EG Disability Act 2005)
 - To develop sectoral plans on disability by 6 key Government Departments
 - New funding for disability services 2004-2009

National Disability Strategy: Legislation

- Disability Act 2005
- Education for Persons with Special Educational Needs (EPSEN) Act 2004
- Citizens Information Act 2007 created a National Advocacy Service for People with Disabilities



National Disability Strategy: Disability Act 2005

- The enactment of the Disability Act 2005 came about as a result of a long campaign by persons with disabilities and civil society for rights based legislation
- A 2002 Bill was withdrawn due to opposition from PWDs.
- 2005 Act is far from the rights based legislation that PWD campaigned for
- No right for a judicial remedy in circumstances where there is failure by state to comply with the legislation.
- Irish courts have refused to enforce the socio-economic rights of PWDs.
 - *Sinnott v Minister for Education* [2001] 2 IR 545

National Disability Strategy



- However, the Disability Act 2005
 - Provides for a statutory assessment of need for health and education services
 - Requires that public services, information and public buildings are accessible for persons with disabilities
 - The sectoral plans on disability – were developed by the 6 government departments
 - The 2005 Act also requires that all public bodies achieve a target of 3% PWDs

The Sectoral Plans



Key Areas

- Communications,
- Employment,
- Environment,
- Health,
- Social welfare,
- Transport.

- The plans out a programme of action and are approved by the Irish Parliament
- Whole government approach
- Great potential
- Modifications to the sectoral plans difficult

Social Partnership & Programme for Government

- The current Programme for Government (2011) & Social Partnership Agreement
 - provide commitments to improving the lives of people with disabilities.
 - and efficient use of allocated resources.
- Range of other policy documents related to PWDs EG (housing, mental health, older persons, carers strategy etc published in recent years)



Implementation: Economic Climate in Ireland

- Banking crisis
- Changed economic environment to 2004 when strategy was launched
- In 2011 programme for government gave a commitment to publish (after wide consultation) a realistic implementation plan for the National Disability Strategy.
- In 2011 Minister for Disability, Equality, Mental Health and Older People – Kathleen Lynch established the National Disability Strategy Implementation Group (NDSIG) to assist in creation of an implementation plan for the National Disability Strategy

Implementation Plan (1)

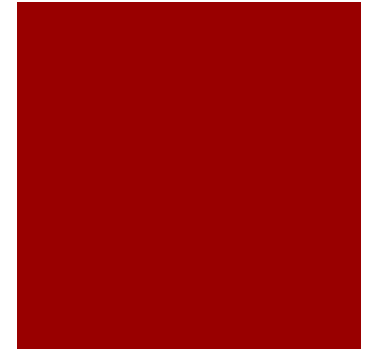
- “National Disability Strategy Implementation Plan: 2013-2015” published in July 2013.
- Plan for The National Disability Strategy and is a whole-of-Government approach to advancing the social inclusion of people with disabilities. This Implementation Plan sets out the practical measures that will be taken to advance the National Disability Strategy over the period 2013 to 2015, and includes commitments relating to the social protection and social inclusion of people with disabilities.
- Since 2008 austerity budgets introduced by successive Irish Governments
- Austerity has resulted in lack of implementation of the the Irish National Disability Strategy.

Implementation Plan (2)

- Disability Federation of Ireland (DFI) critical of the plan as lacking ambition.
- The implementation plan does not refer to supports such as Personal Assistance.
- Timelines for implementation are weak – continual references to “ongoing” implementation.



Good Strategy Poor
Implementation



Government = Implementation
deficit disorder

Success Factors for Disability Strategies

1) Leadership: Leadership by both civil society & government actors is crucial for successful implementation.

2) Participation of Persons with Disabilities in Implementing and Monitoring the National Disability Strategy: This involves much more than mere consultation – ensure deaf & hearing impaired & persons with intellectual disability are included.



Success Factors for Disability Strategies

3) Integrating the National Disability Strategy with Domestic Implementation of the Convention on the Rights of Persons with Disabilities (CRPD): Avoid duplication of work & promote a coordinated approach. NDSs necessary for state party to achieve its obligations under the CRPD.

4) Positive Legal Obligations and Funding Programmes to underpin the National Disability Strategy: Obliging actors to take proactive measures to combat discrimination against particular groups can be effective in reducing discrimination, especially in the employment sphere. The types of legal obligations in question are duties to be proactive in promoting equality.

The failure to cost the implementation of National Disability Strategies has been identified as a major barrier to success in a number of jurisdictions. A costed funding programme should be a key feature.

Success Factors for Disability Strategies



5) Transparency and Accountability in Reporting on Progress in Delivering the National Disability Strategy: Government needs to be honest about progress & the barriers encountered. Identifying these barriers is the first step in dismantling them to ensure more successful implementation. People with disabilities have a right to the relevant and accessible information.

6) Mainstreaming Disability Equality: Mainstreaming disability equality in generic policy development helps to identify systemic barriers affecting persons with disabilities. This provides policy makers with an opportunity to reassess the purpose of the system in question and whether it is achieving its aim of serving all members of the public. Policy makers need to consider PWDs & impact of policy on them.

Success Factors for Disability Strategies



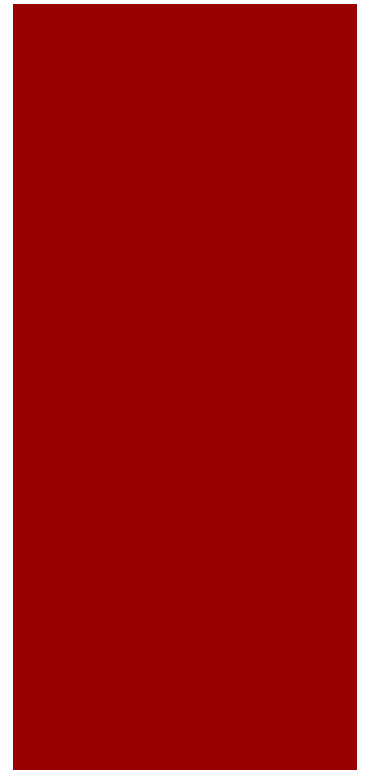
7) Independent Monitoring and Review of National Disability Strategies: Many National Disability Strategies use self-reporting by government departments and public bodies to measure progress in implementation. Essential that reporting structure is independently monitored to present an accurate picture of progress.

8) Indicators and Data – Measuring Implementation and Monitoring: Need for statistical measurement of the impact of the initiatives introduced by a National Disability Strategy, which can be used in order to determine effectiveness of these initiatives and the strategy as a whole.

Conclusions

- DPOs critical of lack of implementation of the National Disability Strategy
- Need for a coordinated approach identified in the Strategy but not fully implemented in practice.
- Key elements such as the employment strategy not developed.
- Allocated resources
- Need for greater inclusion of persons with disabilities in implementation.
- Success factors should form part of a National Disability Strategy for Ireland.





Part 2: Legal Capacity Law Reform in Ireland

Legal Capacity in Ireland

- Currently Irish law is a mix of: Functional / Status / Outcome approaches
 1. Functional approach (Fitzpatrick v FK, The Attorney General [2008] IEHC 104)
 2. Status approach EG having a disability = incapacity – Regulation Lunacy (Ireland) Act (1871)-person of unsound mind and unable to manage person or property & Power of Attorney Act 1996
 3. Outcome approach EG a person disagrees with a proposed decision can be interpreted as the person lacking capacity

The Need for 2013 Bill?

- UN Convention on the Rights of Persons with Disabilities + other human rights obligations
- Equal treatment of persons with disabilities along with everyone else in aspects of life
- Focus will be on helping people to make their own decisions
- Provide proper safeguards when questions raised over a persons decision-making...



The Need for 2013 Bill?

- Ward of Court system (Lunacy Regulations (Ir.) Act 1871) will end – substitute decision making
- This Bill is not law yet so might change-for example:
 - it applies only to those over 18s now-what about 16-18 year olds?
- Will need detailed Codes of Practice to make it work



New Capacity Legislation



- The new capacity legislation seeks to strike the correct balance between autonomy and protection.
- It remains to be seen whether the correct balance will be struck.
- Some of the commentary on the Scheme of the Bill published in 2008 suggested that the legislation failed to strike the appropriate balance.
 - Oireachtas Justice Committee Hearings 2012
 - Advocacy lobbying resulted in changes to 2008 Scheme
- Assisted Decision-Making (Capacity) Bill 2013

Assisted Decision-Making (Capacity) Bill 2013

- It was published on 17 July 2013
- Developed in the Department of Justice – civil section



Terminology in the 2013 Bill



- Relevant person (RP)-person who may have decision making difficulty-focus should be on this element
- over 18, whose capacity is in question or shortly to be in question regarding one or more matter
- Person who lacks capacity regarding one or more matter
 - Appointer of a decision making assistant
 - Donor of an Enduring Power of Attorney

Principles to Guide the Law



- Presumption of capacity for everyone
- A person will not be considered unable to make a decision unless all efforts have been made to help in making the decision without success
- Information must be easily understood/relevant
- Unwise decisions can be made without the person being deemed unable to make a decision

Principles to Guide the Law



- Interventions with the person should be made only when it is necessary and interfere as little as possible with the person's rights and freedoms
- When making an intervention the participation of the person should be encouraged as far as possible
- Any interventions should ensure the person's past and present will and preferences should be respected as far as practicable-
- Consult others including those caring for the person, interested in the person and healthcare professionals

Capacity in the Bill means:



- Functional definition
- Ability to understand nature and consequences of a decision to be made by RP in the context of available choices at the time the decision is to be made...NOTE:
 - Information crucial
 - Assessor's role crucial

Assessing Capacity

- Understand the information relevant to decision
- Remember it (even for a short period may be enough)
- Use or weigh that information to make a decision
- Communicate by any means- assistance, 3rd party etc.



Categories Proposed in 2013 Bill



- ① Decision Making Assistant
- ② Co-Decision Maker
- ③ Decision Making Representative
- ④ Informal decision maker – major area
- ⑤ Court ordered interventions-emergency and others

Other Supports

- Attorney under Enduring Powers of Attorney – extended to health care
- Proxy in Advance Healthcare Directives

1) Decision Making Assistance

- The person has capacity to appoint “another” to help in making decision/s on finance/ property or personal welfare –someone person knows and trusts
- Both must understand duties and obligations
- They make a Decision Making Agreement + Public Guardian notified
- If someone later disagrees with the person the agreement can be shown to support the person



Role of DM Assistant

- Advises and explains relevant information
- Discovers the persons wishes (will and preferences) and helps the person to communicate them
- Helps with getting information /personal records- strong privacy/confidentiality rules
- Helps the person to express wishes and make decision
- “Endeavour to ensure” decisions are implemented



2) Co-Decision Making

- The person can be “appointer” of a “suitable” person as co-decision-maker
- They jointly make agreement specifying issues and decisions + co-sign documents-
- Application to Court for Co-Decision Making Order
- Where CDM order made-decisions are void unless jointly made
- Decisions will be considered to have been made by the person
- Changes to the order must have court approval
- The agreement has no legal basis without the order

Who can be a Co-Decision Maker?

- Must be “suitable”
- means a relative/friend who has had ‘such personal contact’ ...over ‘such period of time’ that a ‘relationship of trust exists’
- + is capable of effectively performing the functions
- More than one CDM can be appointed but only one involved for each decision



Co-Decision Making Role

- Role in advising “may do all things necessary” to carry out the agreement
- Must discover the “will and preferences” of person and assist in communicating these
- Assist person to get information, records with consent – (strong privacy/confidentiality rules)
- Help /Assist to make the relevant decision
- “Endeavour to ensure” decisions are implemented



3) Decision Making Representative



- Where the person is deemed to lack capacity even with assistance of Co-Decision Maker -
 - Court can make decision if matter is urgent
 - Or Appoint Representative for one or more decision
- Where no suitable person/s “willing or able” can request from a Panel of DMRs from the Public Guardian
- Court can give powers/duties/ conditions
- Power is to be limited in scope as possible

DM Representative: Their Role



- Acts as agent of the person
- Scope relates to personal welfare/finance property:
 - Where person lives, with whom has contact,
 - Employment/training/rehab
 - Consenting/refusing continuation of treatment (except refusal of life sustaining treatment)
 - Personal papers
 - Travel outside state
 - Other matters court considers necessary

DM Representative: Their Role



- Property and affairs including:
 - All Property and business matters, discharge of debts, tenancy matters, contracts
 - providing for others as expected,
 - conduct of court proceedings,
 - applications for housing,
 - advancing the interests of the person

DM Representative Safeguards



- Court Power to stop or vary if Representative acts outside the scope granted
- Representative cannot prevent a particular person from having contact with the the person
- Must have court approval for settlement of property for benefit of the person or others

4) Informal Decision Maker

- Decisions can be made for the person on personal welfare including healthcare and treatment.
- The informal decision maker will be protected from liability provided it's a decision the person would make if he or she had capacity
- Also the informal decision maker must abide by the Principles to avoid liability
- The informal decision maker is responsible if acts negligently



Restraint

- Bill Defines Restraint as:
 - using or indicating intention to use force to “secure the doing of an act which the relevant person (RP) resists”
 - Restricts RP’s liberty of movement regardless of resistance or
 - Authorises another to do any of above
- Do more than restrain if s/he deprives person of liberty



Restraint

- Other Sections of the Bill provide that the Representative, Informal Decision Maker and Attorneys under Enduring Power of Attorney have specific and limited authority to restrict a person's liberty which must fall short of deprivation of liberty
- Deprivation of liberty will be limited to the courts apart from mental health legislation



5) Decision Making Authority: The Court

- Circuit Court mainly
- Except High Court only for specific healthcare decisions-non-therapeutic steril, withdrawal of life sustaining treatment, organ donation
- Held in private and informal as possible
- Emergency orders as well as other orders
- Court can direct expert medical, financial, healthcare prof reports –



Court

- Parties to proceedings who have legal representation are liable for costs
- Court may order all or part costs paid out of assets of person if not eligible for legal aid
- Where no legal rep or other support may be assisted by court friend-who assists and promotes interests –
- “the Court shall have all such powers as are necessary to assist it in making a decision” for a declaration re capacity , orders or review.



Informal detention = deprivation of liberty



- De Facto detention or deprivation of liberty under European Convention on Human Rights means:
 - complete and effective control by staff over medication and supervision over assessment, treatment, care, residence, movement - HL v UK (Bournewood)
 - Applies not just to mental health care settings but also to social care settings Stanev v Bulgaria
- Where are the safeguards? For voluntary admissions who have impaired capacity-eg persons who are in residential care but subject to high levels of supervision and control? Raises important human rights issues.

Current Wards of Court under 2013 Bill



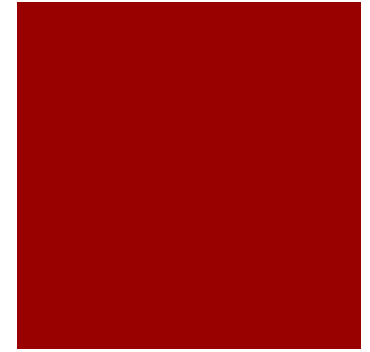
- Review automatically in 3 years or on application
- Court discharge from wardship where ward has capacity can make orders EG return of property
- Where ward lacks capacity unless assisted by CDM or even if CDM available Court makes declaration and discharges from Wardship to come within provisions of new law
- Can then appoint a Representative or / and can transfer supervision of existing Wards to Public Guardian

Enduring Power of Attorney



- Form of advance directive personal appointment of attorney-person understands what they are doing
- Guiding Principles apply
- Includes healthcare decisions but are limited to those where the person (donor) lacks capacity or may shortly lack capacity
- Includes giving/refusing consent to treatment apart from refusal of life sustaining treatment
- More supervision over process than under current 1996 Act

Office of the Public Guardian



- Supervisory functions/keeping registers
- Appointing panels of special and general visitors, court friends, DMRs,
- Receive complaints, investigation, consult widely
- Raise Public awareness + Website and advise bodies with interest as required under UN CRPD
- Publish Codes of Practice
- No reference to Advocacy service for key decisions...

The Law Reform Process

- Long road
- Multiplicity of actors
- Important role of DPOs and civil society organisations coming together to fight for more CRPD centered approach
- Persistence



10 'Essential Principles: Irish Legal Capacity Law'



- Developed by a coalition of disabled persons organisations, older persons organisations, civil society and academia etc.

10 'Essential Principles: Irish Legal Capacity Law'

1) All human rights apply to all people equally – without discrimination on the basis of disability. This includes everyone's right to make choices and decisions about their life.

2) All adults have a right to make their own decisions for themselves and to exercise their rights ('legal capacity') and must be given the supports they need to be able to make decisions.

10 'Essential Principles: Irish Legal Capacity Law'

- 3) People who need support to make decisions have a right to be provided with that support by the State, EG advocate supports should be recognised and assist the persons in understanding the options and expressing their “will and preferences”

4) The law should allow people to plan in advance and have such decisions protected in law. There should be awareness raising and education around the option to make plans in advance.

10 'Essential Principles: Irish Legal Capacity Law'

5) A person retains their fundamental rights EG to vote, marry, etc. even if they are getting support to make a decision or someone else is making a decision for them.

6) Strict safeguards must be put in place to protect the human rights of people who are supported in making decisions, or who have someone making a decision for them.



10 'Essential Principles: Irish Legal Capacity Law'

7) Decisions made by someone else for a person is a last resort when all supports have been considered (facilitated decision-making). It should only apply for specific decisions and for the length of time necessary for that purpose.



10 'Essential Principles: Irish Legal Capacity Law'

8) Decisions made by someone else for a person is a last resort when all supports have been considered (facilitated decision-making). It should only apply for specific decisions and for the length of time necessary for that purpose.

9) All information processes and procedures must be easy to understand, must have the person at the centre of the process and must meet the person's individual needs. This means that a court based system, which determines capacity is not appropriate.



10 'Essential Principles: Irish Legal Capacity Law'

10) When somebody else is being appointed as a decision-maker for a person (facilitated decision-making), the person should have the opportunity to take part in the process and be fully represented, keeping in mind that a facilitated decision-maker should be only appointed where the “will and preferences” of the individual is not known.



Conclusions

- When enacted significantly improve the recognition of persons with disabilities as rights holders entitled to make decisions on an equal basis with others.
- Empowers persons with disabilities to fend off third parties who questions their decision-making
- There is a renewed focus on supported decision-making
- However, it retains elements of the functional approach and provides for substitute decision-making





Thank you for your attention. Any questions???

References / Useful Links

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