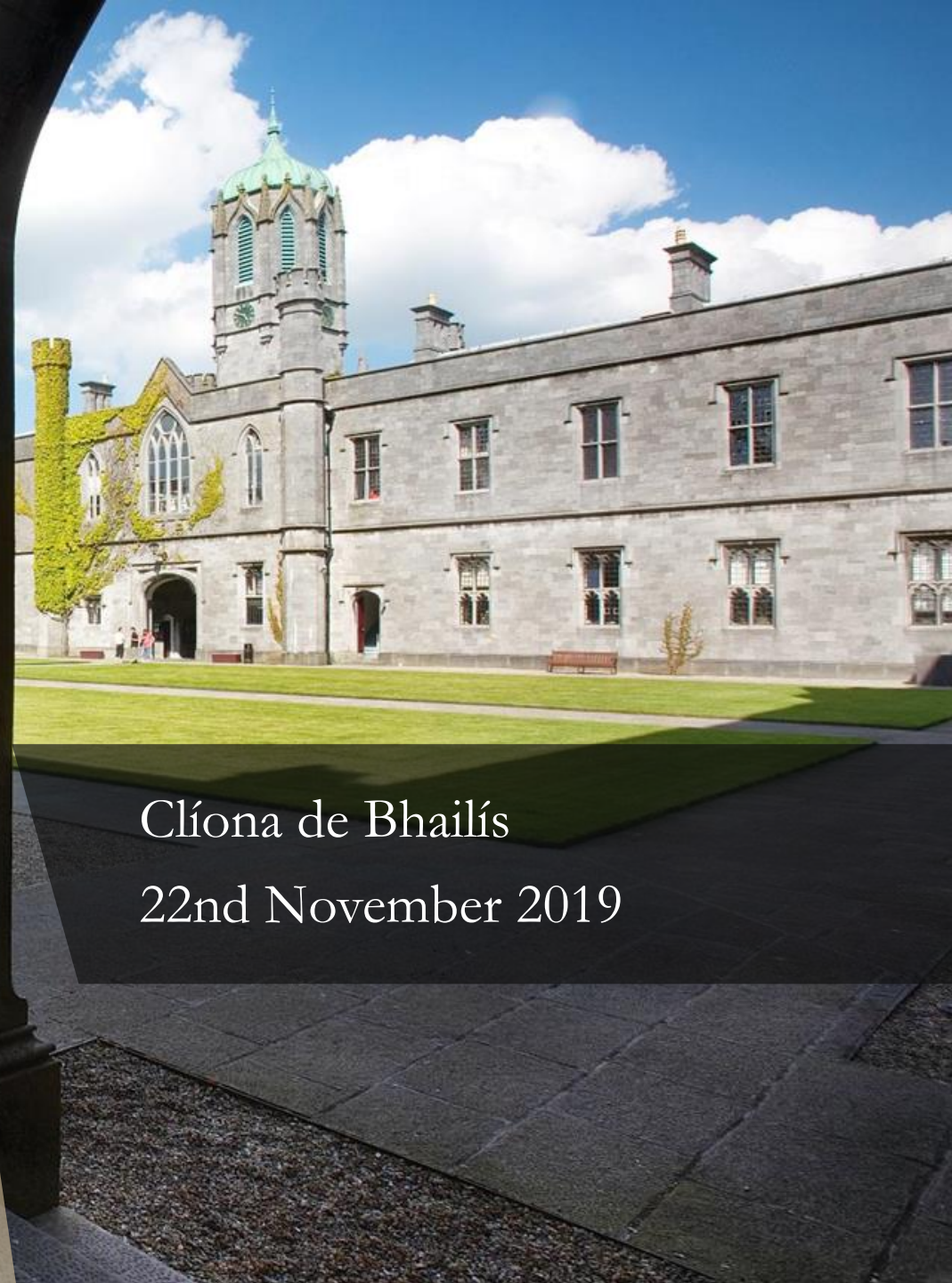




NUI Galway
OÉ Gaillimh

UNCRPD and young people with palliative care needs



Clíona de Bhailís

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Overview

- UNCRPD & Ireland
- Children with disabilities
- Legal capacity
- Support for decision making/participation
- Hard Cases

UNCRPD & Ireland

- Adopted by the UN in 2006
- Ireland signed CRPD in 2007 & ratified in 2018
- Broad concept of disability Article 1 CRPD
- Articles on a broad range of rights incl. right to health (Art. 25), accessibility (Art. 9), education (Art. 24), independent living (Art. 19)

Article 3 – General Principles

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Article 7 – Children with disabilities

- Human rights on an equal basis with others
- Best interests primary consideration
- Right to express views on all matters affecting them and their views should be given due weight based on age and maturity
- Provided with disability and age appropriate assistance

Article 12 - Equal recognition before the law

- Recognition as a person before the law
- The right to make decisions which have legal consequences and to have those decisions respected by the law
- Move from best interests to will and preferences
- Children with disabilities must have their will and preferences respected on an equal basis with other children

Best interests vs will and preferences

Best Interests (Article 7)

Judgement by third party about what is 'best' in a particular circumstance. 'Objective' standard.

Will and Preferences (Article 12)

Will

Vision of the good life
Overall plan for our lives

Preferences

Likes and dislikes
Priorities we give to things

Support

- Broad term encompassing formal and informal arrangements
- Vary in type and intensity based on the person and their needs
- General Comment No. 1 recognises the evolving nature of the field and many and varied individual support needs

Common Misconceptions

- Not everyone will wish to exercise their right to support and support cannot be imposed
- Support should be open to everyone – including people with complex or high support needs or who communicate differently

National Consent Policy

- Respect for children’s autonomy should be integrated into decision-making in the same way as adults
- “....respect for the autonomy of the child entails the facilitation, wherever possible, of the child’s right to make his/her own decisions”
- Policy directly quotes paragraph 3 of Article 7 CRPD

Examples of support/assistance



Accessible Information



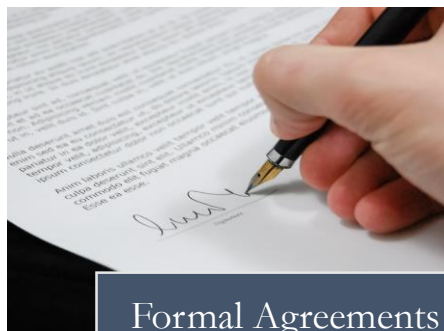
Advance Planning



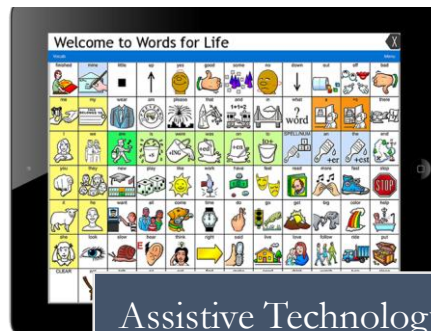
Peer Support



Circles of Support



Formal Agreements



Assistive Technology



Self Advocacy

Support & Informal Communication

- Dr. Jo Watson, Deakin University
- 5 individuals with complex/high support needs using unintentional/informal communication & their circles of support
- Examined the forms of communication people were using and identified key decisions in the person's life to support them to make using this information
- Included decisions on daily routine, finances, health care

Hard Cases

Will and preferences are unknown

For example: Coma patient

Article 12 Approach: Best interpretation of will and preferences



Hard Cases

Will and preferences in conflict

For example: Person with a toothache who refuses to go to the dentist but wants the pain to stop

Article 12 Approach: Work to resolve the conflict

