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Research in Populations with Complex Learning Needs

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Doctoral Programme in Clinical Psychology

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Legislation

- **National Disability Strategy (2004)**.... people with disabilities should be supported to be active and contributing members of society.
- **Citizens Information Act (2007)**...providing certain advocacy services to people with disabilities.
- **The Mental Health Act (2001)** - checks and balances for people in approved centres offering treatment for mental illness.
- **The UN Convention on Individuals with Disabilities (2008)** ...*Persons with disabilities can exercise the right to freedom of expression and opinion (Article 21)...*
- *Enable persons with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society (Article 30).*

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Ethically Sound Research

- Involves values and judgements that bring together the academic; the professional; the personal and are coded as:
 - Trust
 - Truthfulness
 - Honesty
 - Integrity
 - Respect
 - Impartiality and fairness
 - Accuracy
 - Openness
 - Reflexive awareness

(Drake & Heath, 2011)

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Major Ethical Principles

- Informed consent.
- Minimisation of potential harm/deprivation of benefit.
- Confidentiality & protection of privacy.

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Informed Consent

- Refers to disclosure by the researcher, before the study, of what will happen during the study and of any other information that might affect the person's decision about whether or not to enter the study.
- It involves:
 - Adequate information
 - Freedom of choice
 - Competence

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Informed Consent

- Difficulties arise when the person's understanding of the issues is limited.
 - Children or adults who are not fully competent to make their own decisions.
 - Intellectual disability and other "clinical" populations (as an example)

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Important Issues

- How information is given?
 - Level of readability
 - Comprehensibility of the study description.
- To whom is info given?
 - Advocates
 - Professional carers
 - Family
- What information is given?
 - Avoid technical language
- Processing Time?
 - Be aware of cognitive deficits
 - may take longer to process?

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Practical Issues

- Appropriate data gathering strategies (assistive technologies for example)
- Interview duration
- Interview Setting.
- Rapport & trust.
- Questioning style.
- Importance of “Facilitated Communication”
 - Use of advocates / loco parentis

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“Other” Issues

- Participants legal status/standing.
- Consent versus Assent.
- Individual capacity.
- Codes of Professional Practice/Standards/ Best Practice Guidelines will guide us.

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