Ethical Issues in Research with Individuals with an Intellectual Disability

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13 April 2015
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Hello and Thank You

One of 7 campuses of Griffith University
What do I do?

- Research Interest in Ethics and Intellectual Disability
- Have researched and taught bioethics, applied ethics and professional ethics, also researched homelessness and Indigenous issues about impaired decision-making
- Chair of the Griffith University Human Research Ethics Committee (HREC)

  - Guided by the *National Statement on Ethical Conduct in Human Research* (National Health and Medical Research Council (NHMRC) Australian Research Council (ARC), 2007)
  - Set membership with Research Ethics Advisors
  - Also guided by the GU Human Research Manual:
National Statement: Vulnerable Groups

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Outline

• What do I mean by Ethics?
• Research Ethics and Intellectual Disability
• Historical Actions and Influences
• Contemporary themes and challenges
• A Conceptual Understanding
• New Challenges
• Researcher Responsibilities
• Broadening Research Practice
• References
But what do I mean by ‘ethics’?


Escher’s Belvedere

http://www.artchive.com/artchive/e/escher/escher_belvedere.jpg.html
Research Ethics and Intellectual Disability

Out of dark research practices, ethics became important ...
Historical Actions and Influences

• Historical examples such as Nazi Germany and Willowbank Hepatitis Study (Iacano & Carling-Jenkins, 2012; Carlson, 2013).

• Lack of Moral Agency and Moral Personhood (Clapton, 2009).

• Prevalent themes such as ‘lives not worth living’; ‘expendable lives’, ‘non-human’, ‘convenient access with a lack of surveillance and protection, eg institutional care.’

• Significant influence on the emergence of ‘research ethics’ and subsequent guidelines (Iacano & Carling-Jenkins, 2012; Carlson, 2013).
Contemporary themes and challenges 1.

- Recognition of a status of vulnerability (ease in which things can go wrong!)(Iacano & Carling-Jenkins, 2012; McDonald & Kidney, 2012; Carlson, 2013).

- Formal compliance guidelines in codes, national statements, institutional committees etc.

- A dominant theme of ‘Protection’ from:
  - Risk of comfort or distress; Harm; Exploitation; Burden; Injustice, Lack of Respect (McDonald & Kidney, 2012; Carlson, 2013).

- An expectation of attention to details:
  - Informed Consent; Capability, Competency and Decisional Capacity; Inclusiveness and Exclusion; Accessibility in Recruitment, Participation and Understanding; Justice; Burden of Research, Discrimination (Lennox et al, 2005; McDonald & Kidney, 2012; Carlson, 2013; Thomson, Roberts & Bittles, 2013).
Contemporary themes and challenges 2

Lucia Carlson (2013) in her paper *Research Ethics and Intellectual Disability: Broadening the Debates* named 3 contemporary tensions:

1. **Double dangers of inclusion and exclusion**
2. The challenges of defining competence and risk in terms of individuals vs groups
3. The conflicts that arise when pursuing the dual goals of amelioration and elimination of disabilities.
A Conceptual Understanding 1

Clapton, 2009.
A Conceptual Understanding

Ethical Inclusion

- Respectful
- Relational
- Capacity, Capability

CRPD
Legislative Inclusion
Normalisation
Social Model

Technical Inclusion
Functionalist Models
Deficit Models
Beneficence and Paternalism

Profound Exclusion
Deficit models

Being Integral
Research ‘with’ +ve difference
different ways of being human

Rights
Research ‘for’
Focus on Human, Social and Civil Rights
Social Justice
Relieving oppression and exclusion
Personhood respected

Deontological Ethics
Virtue Ethics
Research ‘on’ / ‘to’ -
Focus on Amelioration

Utilitarian Ethics
Research ‘about’
Good = exclusion, non-desired
Non-person
Focus on Prevention, Elimination
Relieving ‘burden’

EMANCIPATORY
Rights-based
Social Justice focussed
Social Policy supported (eg anti-discrimination)
Applied & Professional Ethics

BIOMEDICAL MODEL
Medical Ethics
Clinical Ethics
Bioethics

Clapton, 2015
A Conceptual Understanding

**Rights**
- Research ‘for’
  - Focus on Human, Social and Civil Rights
  - Social Justice
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- **Virtue Ethics**
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**Utilitarian Ethics**
- Research ‘about’
  - Good = exclusion, non-desired
  - Non-person
  - Focus on Prevention, Elimination
  - Relieving ‘burden’

**CRPD**
- Legislative Inclusion
  - Normalisation
  - Social Model

**Technical Inclusion**
- Functionalist Models
  - Deficit Models
  - Beneficence and Paternalism

**Profound Exclusion**
- Deficit models

**Being Integral**
- Research ‘with’ +ve difference
different ways of being human

**Ethical Inclusion**
- Respectful Relational Capacity Capability

**Facilitated Consent**
- Supported Consent

**EMANCIPATORY**
- Rights-based
  - Social Justice focussed
  - Social Policy supported (eg anti-discrimination)
  - Applied & Professional Ethics

**BIOMEDICAL MODEL**
- Medical Ethics
  - Clinical Ethics
  - Bioethics

**Utilitarian Ethics**
- Research ‘about’
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A Conceptual Understanding 4

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Functionalist Models
Deficit Models
Beneficence and Paternalism

**Profound Exclusion**
Deficit models

**Ethical Inclusion**
Respectful
Relational
Capacity
Capability

**CRITICAL DISABILITY STUDIES**

**EMANCIPATORY**
Rights-based
Social Justice focussed
Social Policy supported (e.g. anti-discrimination)
Applied & Professional Ethics

**BIOMEDICAL MODEL**
Medical Ethics
Clinical Ethics
Bioethics

Clapton, 2015
Article 3 - General principles:
The principles of the present Convention shall be:

a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;

b) Non-discrimination;

c) Full and effective participation and inclusion in society;

d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e) Equality of opportunity;

f) Accessibility;

g) Equality between men and women;

h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

United Nations Convention on the Rights of Persons with Disabilities

Article 11 - Right to life

Article 12 - Equal protection and equal recognition before the law

Article 13 - Access to justice

Article 14 - Liberty of movement and nationality

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 16 - Freedom from exploitation, violence and abuse

Article 17 - Protecting the integrity of the person and security of the person

Article 18 - Liberty of movement and nationality

Article 19 - Living independently and being included in the community

Article 20 - Personal mobility

Article 21 - Freedom of expression and opinion, and access to information

Article 22 - Respect for privacy

Article 23 - Respect for home and the family

Article 24 - Education

Article 25 - Health

Article 26 - General obligations

Article 7 - Children with disabilities

Article 8 - Awareness-raising

Article 9 - Respect

Article 10 - Right to life

Article 11 - Situations of risk and humanitarian emergencies to justice

Article 12 - Accessibility

Article 13 - Access

Article 14 - Awareness

Article 15 - General obligations

Article 16 - Non-discrimination

Article 17 - Family

Article 18 - Equality and non-discrimination

Article 19 - Situations of risk and humanitarian emergencies

Article 20 - Personal mobility

Article 21 - Freedom of expression and opinion, and access to information

Article 22 - Respect for privacy

Article 23 - Respect for home and the family

Article 24 - Education

Article 25 - Health

Article 26 - General obligations

Article 7 - Children with disabilities

Article 8 - Awareness-raising

Article 9 - Respect

Article 10 - Right to life

Article 11 - Situations of risk and humanitarian emergencies to justice

Article 12 - Accessibility

Article 13 - Access

Article 14 - Awareness
Implications & Emerging Challenges

Impact of the CRPD (2006) and the stated articles and Understanding the impact of different Models of Disability (Critical Disability Studies – CDS):

• Models of Consent (Stainton & Clare, 2012)
• Accessibility and non-accessibility (including communication – how and who?)
• Research design and data collection and interpretation – consistency, coherency, values clashes (Coons & Watson, 2013)
• Self advocacy and participatory research
• Education for new researchers and ethics committees (Iacano & Carling-Jenkins, 2012)
Other Implications & Emerging Challenges

– Ongoing exclusion
  • Professional and organisational gatekeeping
  • Dominant presumptions – too hard
  • Dyad / triad research and freedom to cease
  • Voice and communication
  • Failure to make accommodations

– Respect for Persons – eg timeliness, accessibility, recruitment and participation

– Intrinsic or instrumental value of the research – for whose benefit?

– Impact of normative values eg. In research instruments

– Cultural factors (Glasson et al, 2005)
Researcher Responsibilities

• To be aware of:
  – Responsibilities for ethical research – be prepared to navigate the ‘maze’ (Thomson, Roberts & Bittles, 2014)
  – Own standpoint – position, professional gaze, paternalism, power and presumptions
  – Own limitations
  – Research design and coherency (Cleaver, Ouellette-Kuntz & Sakar, 2010)
  – Being accountable (McDonald & Kidney, 2012, Wiese, 2014) and trustworthy (Iacano & Carling-Jenkins, 2012)
  – Being prepared to educate Ethics Committees (Iacano & Carling-Jenkins, 2012)
Broadening Research Practice

• Inclusive / participatory research in design and recruitment (Iriarte, O’Brien & Chadwick, 2014).
• Widening the populations / diversity of participants (people with ID as part of the population) – eg in Clinical Trials (Fisher et al, 2006); Public Health Research (McDonald & Raymaker, 2013).
• Respecting the CRPD (2006)
• Being ‘critical’ of ‘what is’ and seeking something inclusively better.
• Role of Ethics
References


References


References


