What are Essential Elements of Ethical Genetic Counselling?

Workshop
Thursday 30 October 2008
Royal Brisbane & Women’s Hospital
Questions for Discussion

1. What are current ethical practice standards?
2. What ethical problems commonly arise in practice?
3. What ethical insights might the humanities offer?
1. What are current ethical practice standards?

- **Professional practices**
  - Reports by practitioners and clients
  - Empirical observations
  - Theoretical descriptions

- **Professional codes of ethics**
  - Mid-20\textsuperscript{th} century moral change from eugenic genetic advice to non-directive genetic counselling
  - Beauchamp & Childress’ 4 principles of health care ethics: respect for autonomy, nonmaleficence, beneficence, justice.
  - Professional differences/similarities
  - Cross cultural differences/similarities
2. What ethical problems commonly arise in practice?

Genetic counselling about testing for Down syndrome in the fetus

- The client as rational, decision-making individualised subjects.
- Science and technology as rational, progressive, objective.
- Down syndrome:
  - a widespread cultural anxiety.
  - The fetus as the other of a rational, decision-making individualised subject.
  - Assumption that women will or should end a pregnancy if they discover that the fetus has a disabling trait.
- Tests for Down syndrome in the fetus:
  - Poor predictive ability of the extent of effects on the fetus.
  - ‘Diagnosis’ – high stability & certainty; amniocentesis, CVS.
  - ‘Screening’ – less stability & certainty:
    - 1970s and 1980s: ‘advanced maternal age.’
    - 1990s: maternal serum + ultrasound screening have extended surveillance to potentially all pregnant women.
- The new discourse of the imperfect in practice: a medicalised and biologised model of disability with a genetic base frames parents' decisions to test and abort (Rothschild 2005)
  - Rate of detection of DS by prenatal testing: 70% of DS ‘cases’ in Victoria (Halliday & Muggli 2004: 470).
  - Rate of termination of a fetus identified with Down syndrome in a range of developed countries: 92% (Mansfield et al 1999) – unintended ‘eugenic’ outcomes?
3. What ethical insights might the humanities offer

Genetic counselling

- A **somatic ethics of biological citizenship** (Rose 2007: 74).
- Genetic counselling as a communication **technology of the self** (Foucault 1988), which constructs cultural meanings of an ethical self for the **health professional** (non-directive, ?) and **client** (genetically responsible).
- Genetic counselling as a political practice of surveillance, discipline and regulation of bodies to conform to particular normative standards.
- Genetic counselling as a **boundary object** (Star & Griesemer 1989) within a **standardised genetic prenatal testing package** (Fujimura 1988) formed from complex and dynamically fluid **assemblages** of clinics, bodies, affect, scientific & other ideas, brochures, consent forms, screening, diagnostic & other technologies & techniques, regulatory policies & practices.
- **real-imaginary-symbolic inter-relations**
- concepts of ‘relational autonomy’ (Mackenzie & Stoljar 2000; Donchin 2000)