Western Australian Register of Developmental Anomalies

Achieving mandatory notification of cerebral palsy in Western Australia - A success story
Western Australian Register of Developmental Anomalies

Birth Defects Register

2011

Cerebral Palsy Register
Co-authors

Prof Carol Bower
Head
WARDA

Anne McKenzie
Consumer Advocate

Hayley Haines
Consumer Project Officer
Background to the WA BD and CP Registers

Both registers amongst the longest standing worldwide:

- **CP Register commenced 1977**
  - Includes cases from birth-year 1956

- **BD Register commenced 1980**
  - Includes cases from birth-year 1980
Register methodologies

- Voluntary notification: No requirement for consent
- Active ascertainment from multiple sources
- Overseen by advisory committees that included parent representatives
The need for change

1988-2001: National Privacy legislation
2002: Voluntary notification becoming less effective
2004: Minister for Health supportive of mandatory notification but wants input from consumers.
How consumers were key to achieving mandatory notification
Involving the Community

2005: Focus groups commence

Consumers asked to choose between 3 options:

- Voluntary notification as previously
- Requirement for consent
- Mandatory notification

Lack of consensus
Involving the Community

2006: Further community consultation

- Telephone survey
  - 96% thought BD/CP register would be useful
  - 6% aware that register already existed
  - 79% supported mandatory notification
- Consumer workshops
  - Consensus achieved
Final outcome

• Unanimous decision in favour of mandatory notification

• Important that information be provided to parents and wider community

• Consumers to be involved in development of new model
Community Reference Group

2007-11: CRG Input into the New Model

• Naming of combined BD/CP Register
• Drafting legislation
• Development of the information dissemination process
• Developing information materials and website
• Ongoing involvement
Acknowledgements

• Staff of the WA Register of Developmental Anomalies
• Advisory Committees
• Community Reference Group
• Community consultation participants