Empty Cots, Broken Hearts

40 – 60% of women with ID will have a baby/child removed from their care.
Maternity care for Women with Intellectual Disability

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Presentation Outline

• Context for Maternity Care
  – Why is this topic important?
  – Current Philosophies & Policies

• Literature - What do we know already?

• What are the gaps?

• Proposed Research
Context for Maternity Care

• Disability policies support an inclusionist philosophy & right for self-determination;

• Parenting for people with intellectual disability:
  – Parenting programs & ‘good-enough’ parenting V parenting within an inclusive society

• 40-60% parents with ID have at least one child removed from their care;

• Implications for families, Government departments; policies, budgets, NGOs
Maternity Care Policies

- Current Maternity Care underpinned by:
  
  Perinatal Mental Health & the ‘Families NSW Supporting Families Early Package’ (NSW Health 2009)

Perinatal Mental Health

The primary care-giving relationship has significant effect on an infant’s bio-psycho-neurologic brain development:

- Conception to 2-3 years
- Poor early attachment can lead to decreased resilience and social responses when infants become adults;
- Screening for women at risk during pregnancy paramount
- Women identified as vulnerable/ at risk are referred to appropriate services based on level of care.
**Antenatal Screening**

**Edinburgh Post Natal Depression Scale (Antenatal)**

(Cox JL, Holden JM, Sagovsky R. 1987)

As you are about to have a baby we would like to know how you are feeling. Please **underline** the answer which comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today. Here is an example, already completed.

I have felt happy:
- Yes, all the time
- Yes, most of the time
- No, not very often
- No, not at all

This would mean: “I have felt happy most of the time” during the past week. Complete the other questions in the same way.

<table>
<thead>
<tr>
<th>PSYCHOSOCIAL ITEMS</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>Emotional support</td>
<td>Yes</td>
</tr>
<tr>
<td>Recent stresses</td>
<td>No</td>
</tr>
<tr>
<td>Generally feel confident</td>
<td>Yes</td>
</tr>
<tr>
<td>Worry about mess</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>No</td>
</tr>
</tbody>
</table>

**PREGNANCY MAY BRING BACK CHILDHOOD MEMORIES!**

- History of childhood abuse: No
- Child living away
- Department of Community Services
- Other issues or worries: No

**CHILDREN & DOCS**

- No
- Not sure
- Unable to ask

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1. I have been able to laugh and see the funny side of things:
   - As much as I always could
   - Not quite so much now
   - Definitely not so much now
   - Not at all

**EDINBURGH SCALE**

- EDS total score: Score 2
- Answer to EDS question 10: Never (score 0)
- Psychosocial/family issues identified: Date 07/10/2014

**PLEASE SAVE. The last two items will be complete according to the business rule.**

- EOS assessment: Assessment 0-9
- Psychosocial assessment: Assessment

**PLEASE INITIATE support/pathways for ref...**
• ‘Towards Normal Birth’ Policy
  (NSW Health 2010)
  – Focus on normal birth and care by a known midwife

• ‘Woman-centred care’:

  “Focuses on the woman’s individual needs, aspirations and expectations, rather than the needs of the institution or professionals; recognises the need for women to have choice...as defined and negotiated by the woman herself. Recognises the woman’s expertise in decision making.” (Leap 2009)

  ➢ Individual focus
  ➢ personal choice within context of family
  ➢ woman as expert
Supporting Policy Documents
Women with Intellectual Disability & Maternity Care

What do we know
Literature Review

• Research (published in English) mostly focuses on parenting issues & outcomes;

• Most reproductive research focused on issues for women with physical or sensory disabilities.
  – Reflects a ‘hierarchy of disabilities’ (Waxman 1994)

• Most pregnancy & birth research for WWID is in UK, Ireland and Sweden;
Vulnerable Women

• Women with intellectual disability:
  – Are more likely to experience domestic/family violence than women without disability
  – Often considered asexual, but more likely to experience sexual abuse (75-90%);
  – Experience ‘diagnostic overshadowing’;
  – Experience care influenced by the ‘hierarchy of disability’.
Contributing Personal & Social Factors

• Intrinsic:
  – Low literacy
  – Communication issues
  – Dual Diagnosis

• Extrinsic:
  – Negative social attitudes leading to decreased social supports, decreased social connectedness
  – Poverty
  – Family violence
Pregnancy Risks

• WWID are at increased risk for:
  – Anxiety & depression
  – Obesity
  – Pre-eclampsia
  – Premature birth
  – Stillbirth (4 x risk)
  – Small for Gestational Age babies (3 x risk)
Maternity System Shortfalls

- Poor identification of WWID at Booking-in or during pregnancy.

- Lack of appropriate health screening tools (Obstetrix/ EDS)
• Inappropriate health promotion materials & Consent procedures
  85% midwives unsure of adapting information

• Staff difficulties in communicating effectively with women/partners (80% midwives)

• Poor Health provider knowledge & attitudes
• System inflexibility
  – Low V high risk clients
  – Appointments,
  – Hospital stay for partner
  – Lack of disability friendly equipment;

• Collaboration & planning
  – Lack of service co-ordination
  – Poor planning
Pregnancy Experiences

• do understand bodily changes & recognise they are pregnant
• feel the joys and concerns just as non-disabled women do
• feel pressured by family and service providers not to have a baby
• And choose the people best able to support them as parents during their pregnancy, birth and postnatal period.

(Mayes et al. 2006, 2008, 2011)
WWID & Maternity Care Context

Health Theories and Systems; Maternity Care

Disability and Social Theory

Social Expectations Relationships
Pregnancy, birth, Parenting

Pregnancy, Birth & Parenthood

Carers
Relatives; Friends
Health Providers
Social Carers
Proposed Research Project

Research Aim:

• To explore the experiences of women with intellectual disability as they interact with the Maternity system during pregnancy.

• To provide insights into factors that act as either barriers or facilitators in their maternity care during pregnancy from both WWID and health providers’ perspectives.
Research Method

Qualitative – 2 Stages:

Stage 1: Focus groups of health providers (single episode)

Stage 2: Individual interviews with women with intellectual disability (longitudinal)

• 20-24 weeks
• 30-36 weeks
• 6-8 weeks postnatal

Analysis: Grounded Theory methodology
Research Contribution

• Better identification of women with intellectual disability in early pregnancy;
• Understanding of the issues from the consumer and health provider perspectives;
• Development of an appropriate model for antenatal care that meets consumer’s needs;
• Inform appropriate health provider education;
• Inform relevant policy development;
Thank you & Questions
‘Maternity Care for Women with Intellectual Disability’ Presentation

References


Hoglund, B., Lindgren, P., & Larsson, M. (2012b). Newborns of mothers with intellectual disability have a higher risk of perinatal death and being small for gestational age. [Research Support, Non-U.S. Gov't]. *Acta Obstetricia et Gynecologica Scandinavica, 91*(12),


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