

# **“He will be just like his Mum and Dad”:**

## **The children of parents with an intellectual disability**

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## The Donald Beasley Institute



The Donald Beasley Institute is a national, independent, non-profit organisation based in Dunedin, New Zealand. The Institute's mission statement is:

To advance the well-being of people with disabilities in New Zealand through applied research and education with a primary focus on intellectual disability.

# Strengthening Families - Protecting Children

## **When a parent has an intellectual disability**

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# Research Team

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# Research Objectives

- To describe the experiences and perspectives of parents with intellectual disabilities themselves;
- To describe the perspectives of these parents on their interactions with support workers and professionals on the barriers to effective support;
- To describe the perspectives of support workers and other professionals on the barriers to effective support
- To analyse the contribution of different perspectives to an effective support relationship;
- To identify the specific difficulties experienced by support services in supporting parents who have an intellectual disability, and the barriers to adapting services to take account of the parents' intellectual disabilities;
- To identify the indirect effects of legal, policy and resource factors on effective support in New Zealand

# Study participants

- Parents who have an intellectual disability;
- Disability support workers who play a key role in supporting individual parents;
- Other informal or formal support people who play a key role in supporting parents (including family members and foster parents);
- Disability service managers;
- Needs Assessment and Service Coordination staff;
- Child protection workers, Family Support Managers, Lawyers.

# Child outcomes: What do we know?

- The majority of children born to parents with an intellectual disability do not have intellectual disabilities themselves.

However:

- Children of parents with an intellectual disability are more likely than children of other parents to experience intellectual or developmental disabilities themselves.

# Profile of the children

At the time of enrolment in the study there were 23 children, 2 were born during the study making a total at the end of the study of 25 children.

Ages ranged from newborn to late teens.

There were 16 females and 9 males.

Excluding the children too young to assess, 8 out of 20 children were identified by their parent as having some developmental concern commonly stated as:

“a bit slow” or “problems with behaviour”.

# Children's health and developmental issues

- 3 of the 6 preschool children were receiving speech language therapy.
- Range of health concerns reported:
  - Seizures (3)
  - Otitis media (2)
  - Asthma (2)
  - Spinal deformity (1)
  - Arthritis (1).
- For at least 8 of the children there was some reference to abuse.

# Children's experience of family?

- For few children in this study 'family' might mean a reasonably traditional nuclear family.
- Most children were either living with one parent or were in foster care.
- These children could be situated within two broad groupings:
  - Extended interfamily and intrafamily relationships
  - Small, sometimes isolated, units.

# Where children lived and the availability of social support

- For a number of the children their residential address changed frequently.
- Children living with their parent were often in rental accommodation of a poor standard.
- Children entering foster care often experienced a number of moves before a permanent placement was found.
- Children with intellectual disability were more likely to be placed in residential schools or other facilities.

# Paramountcy of the child

- What is the impact of decisions about best interest?
- For the children who were subject to Family Court proceedings arrangements for contact with parents changed regularly.
- From a young age these children may go through periods of frequent, regular contact with their parent/s to periods where they didn't see them for weeks or months.

# Conclusions

- Children of parents with an intellectual disability are at increased risk for developmental disabilities themselves.
- The developmental disabilities that these children experience are not always linked to poor parenting.
- Due to the high rate of child removal from their parents these children frequently experience reduced social support.

# Conclusions

- Formal child, family and disability support services must ensure:
- that the children of parents with an intellectual disability have their social support needs recognised and responded to.
- that parents with an intellectual disability have the same access to social support as other parents who have children with developmental disabilities.

# Future research

- Exploration of the child's experience of the social milieu that characterises the context of parents with an intellectual disability.
- Which children of parents with an intellectual disability are more at risk for developmental disability?
- What do children themselves say about being raised by a parent with an intellectual disability?

# references

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- McConnell, D., & Llewellyn, G. (2002). Stereotypes, parents with intellectual disability and child protection. *Journal of Social Work and Family Law*, 24(3), 297-317.

# Further information

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