

42nd Australasian ASSID Conference

Life experiences of parents with a young adult son or daughter with intellectual disability who share the family home:
Letting go of the pathogenic paradigm

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Introduction

- Research thus far mainly around parents of children and increasingly older adults
- Often assumes life is burdensome, one-dimensional; has a pathogenic focus
- Need for a holistic study that explores the complexities of the parental experience
- Alternative research method to explore the lived complexities in its fullness

Overview

- Parents/ family life at young-adult life stage – launching into adulthood
- The concepts of ‘carer’ and ‘care’ – construction of the carer label
- Parents and secondary stigma
- Family life: Challenging and enriching times
- A qualitative narrative research method

Parents and family life

- 'Perpetual parents' (Shearn & Todd, 1997)
 - parenting role endures into old age
 - 'launching into adulthood' may not occur for person with disability (May, 2001)
- 'Letting go' (Turnbull et al, 2006)
 - independence & interdependence
- Family norms evolve informally over time, and occur as a matter of course as regular 'family business' (Knox & Bigby, 2007)

Construction of 'Carers': Parents as parents

- Carer labelling (Nolan et al, 1996)
 - Devalues parents' roles and responsibilities as parents
 - Diminishes the relationship between the parent and adult/ child with a disability



Construction of 'Carers': Parents as parents

- Most family carers do not identify as carers (Lloyd, 2003)
 - The need to distinguish between 'caring for' and 'caring about' someone (Stalker, 2003)
- Caring categorisation diminishes the true relationship between both the parent and family member with a disability

Parents and secondary stigma

- Stigma by association with a person with intellectual disability
- Stigma and oppression ... parents also disempowered or disabled by society
- Underscores the need for parents' voices to be heard
- Value of parents' knowledge

The complexity of the lived experience: Life as challenging & enriching

- The challenging and enriching duality of life (Kierkegaard, n.d.)
- Personal growth & enrichment
 - 'having a child with intellectual disability often leads to a fuller and richer life' (Knox et al, 2000)
 - happiness, fulfilment, family closeness (Hastings et al, 2002)

The complexity of the lived experience: Life as challenging & enriching

- Transformation
 - the child with a disability as the catalyst for positive transformation (Scorgie & Sobsey, 2000)
- Resilience
 - families have developed ways of dealing with difficulties; ways suitable to their unique (but also common) situation; a part of regular family business

A qualitative method to explore the parental lived experience

- Narrative method
- Small sample
- In-depth interviews, life stories

Hermeneutic Cycle

- In-depth interviews
- Collaborative relationship
- Reflexivity

- Parents' stories and narratives of their lived experience

- Richer & thicker data
- Further understanding

- Knowledge from experts (parents)

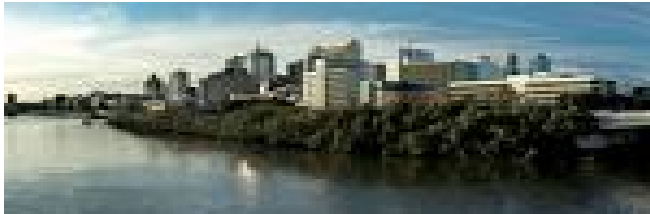
- Member checking
- Feedback
- Confirm data & meaning
- New data to build & generate theory

Narrative as a means of giving voice to the silenced group

- Parents as the experts of their lived experience ... life as it is constructed by them – their story
- Emancipatory research
- To explore and give voice to a multi-dimensional and complex life at this stage of the family life-cycle
- And to let go of the pathogenic view; the simplistic, one-dimensional perception of life as a burden

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