Including children
with disability or chronic illness
in child well-being research:

Methodological considerations

Australia

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This paper

- Overview of study progress

- Identify the importance of including children with diagnosed disabilities in comparative well-being research

- Describe the challenges we confront in attempting to be inclusive in our research

- Outline a plan for a more focussed approach to include children with disabilities and chronic illnesses.

Project progress

- 4 suburban sites – 45 participants
  - Private group near the city of Newcastle
    - Med–High SES; 3 F/3 M; 8 – 11 years
  - 2 Govt After School Care centres South West Sydney
    - Low-Med SES; 11 + 8 participants; 12 F/7 M; 8 – 12 years
  - Catholic High school South West Sydney
    - Med-High SES; 19 participants; 15 F/4 M; 14-16 years

- Data collection stages 1 – 4
  - Maps, Profiles, Filming, photographs, letter writing, my week tool, focus groups on concepts
- Preliminary analysis of methods and data

Why are we concerned to include Children with disability or chronic illness ?

- Same rights as other children to be heard
- Often excluded from total population research on children's lives and experiences
- Indicators for monitoring health and well-being in these populations lacking (Fraser et al 2010)
- Despite some progress in survey research which indicate lower that average well-being and need for more in-depth exploration (Goswami 2014)
- Few qualitative well-being studies have purposively included children with disabilities.

Inclusion in the CUWB qualitative study

- Necessary to extend comparative aspects to include children with disability/chronic illness
- Important to understand well-being in the context of living with disability/chronic illness
- More children survive severe and chronic conditions
- Some transcend challenges and achieve positive outcomes
- For many achieving quality of life can be challenging
- Research with disabled children can highlight the complexity of the way we research with children more generally (Tisdall, Davis & Gallagher 2009)
- Moral imperative – exclusion = discrimination and disempowerment (Carpenter & McConkey 2012)

Challenges in Access and Recruitment

- Mainstream organisations that also provide services for children with disabilities
  - Enthusiastic agreement to be involved
  - No consents from parents parents of children with disabilities

- Specialised organisations
  - Very few responses

Access and recruitment: Ethics Approvals

- Hospital (Government Health)
  - Complicated ethics process – 6-8 months. Approval required from each individual Local Health Districts HREC and site specific approval (SSA) from managers of each particular service/ hospital wards
- Public/Government schools
  - Specific ethics application process (SERAP)
  - Heavy gatekeeping - only State School research priorities will be approved
  - Special schools – further gatekeeping
- Independent schools
  - Easier. Permission can be gained directly from principals.
  - No additional ethics approval
  - Usually limited number of children with disabilities
- Catholic schools
  - Permission from the Catholic Education Office
  - No additional ethics approval
  - Usually limited number of children with disabilities

Study design: Theoretical Principles

- Childhood sociology
  - Children as active in construction …of their social lives… societies in which they live (Prout and James 1990)
- Critical disability studies
  - Framing disability in terms of Social relations (Watson et al)
  - Acknowledge difference between Disabling effect of structural, social and attitudinal barriers and
  - Individual experiences of impairment (physical, cognitive, sensory) (Social Model – Oliver 1990)
  - Approach has been successful in Research with teenagers with autism (Mogensen 2010; Mogensen & Mason 2015)
  - Children with disabilities (Connors and Stalker 2007)

Study design: Methods

Thorough preparation:

- Individual communication and cognitive abilities and preferences
- Pre-research consultations with children and their parents/carers useful
- Involve children in selecting their preferred methods of communicating and participating
- Meet with children several times if they want, to ensure their views are adequately understood and included
- Be reflexive throughout the implementation and allow for change and extra time

(Mogensen 2010; Mogensen & Mason 2015)

Extending CUWB Methods

- A range of flexible methods developed which children have enjoyed

- Many of these will be suitable for children with disabilities

- May still require adjustments

- May require learning some new skills or partnering with people with particular abilities

(Mogensen 2010, Watson 2012)

Setting up a pilot study

- Catholic School for children with disabilities
  - Mainly mild to moderate cognitive impairment
- Networking approach: Personal contacts and direct approach
- Specific rationale of interest for the school and parents/caregivers for including children with disability – the why? questions
- Inclusion with mainstream activities is one of the key missions for this school

Next steps

- Funding
- Partners within Australia and internationally
- Other researchers in the CUWB project
- We welcome
  - Input and ideas on how to best achieve goals
  - Experiences in inclusive research methods
  - Interest in being involved
  - Interest in collaborating on implementing inclusive process into multinational child well-being project

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