Juggling Work & Care

Impacts of caring for a child or young person with disability

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Who is a carer?

- Exceptional caregiving responsibilities (*Roundtree & Lynch, n.d.*)
- Dominant home-based care model for children and young people with disabilities
- Economic importance of unpaid carers
Impacts of care

- Parent carers are vulnerable to mental health & other difficulties (social, emotional, physical)
  - Characteristics of disability (behaviour problems)
  - Social support
  - Other risk/ protective factors?
Study 1: Time to Care

- Consequences of caring on the daily activities of parents of preschool aged children with developmental disabilities?
- Partnership with Disability SA
- Mixed methods
  - Semi-structured interviews (x 95)
  - Standardised questionnaires
  - 24 hour time use diaries
Key outcomes (time use diaries)

Study parents spent:

- Substantially more time in “active” care (physical care; emotional care; teaching/ helping/ reprimanding)

- Substantially less time in “passive care” (minding)

- The same amount of time more “qualitative” care activities such as playing/ reading/ talking to child
Child care mostly a secondary activity for parents of children without disabilities
Study 2: Juggling Work & Care

- What are the impacts of care on participation in paid work and factors influencing this for parents of children and young people with disabilities (2-25 years)?

- Does paid work have a role in protecting the mental health of carers?

- Quantitative methodology
  - Surveys from 416 PCGs and 235 SCGs
  - Clients of Novita and Disability Services SA
Key outcomes: Work participation

Caring significantly impacted plans for mothers to return to work and remain in the workforce, particularly for:

- Sole mothers
- Those caring for children and young people with more severe disabilities
Employment status of mothers – Age of child
Key outcomes:
Impacts for work (mothers)

► Needing to work part-time to fit in care
► Unable to take higher level duties or promotions due to part-time work
► Unable to study or do professional development activities
► Limited job opportunities due to the need for workplace flexibility
► Impact of emotions on ability to work
► Financial strain (↓superannuation savings)
Hours of work (fathers)

- JW&C fathers (SCG)
- Weston et al 2004 (Fathers, HILDA data)
Impacts for work (fathers)

- Reduced earning capacity and career opportunities
- Can lead to changes in work status (self-employment?)
- Impact on job performance
- Security & financial need vs. quality of role

“I am stuck doing something I don't enjoy because it earns me enough money to provide for my family. I am 45 and can't afford to take risks at this stage as it will impact heavily on our financial future.”
Key outcomes: Work and well-being

Psychological distress (PD: K10)

- 47% mothers experienced PD
- 43% fathers experienced PD

Mothers (especially sole mothers) in paid employment were significantly less likely to report PD than those not in paid employment

“The challenge of work makes me a better parent, as I'm happier.”

“I can forget about (sometimes!) being a carer for a few hours and think about other things than complicated medical diets, appointments and therapy.”
Caveat

- Work participation is part of the mix of factors supporting good mental health particularly for sole mothers BUT
- Not a simple story - issues of choice, financial capacity, quality of disability supports, workplace factors....
- Maternal health, caregiving stress and time pressure are important contributors to PD
Study 3: Focus on sole mothers

- In-depth interviews with 11 mothers of school-aged children with disability

Primary themes:
- Importance of support from family and friends
- The challenge of accommodating a child’s therapy and medical appointments
- Some workplaces are more supportive than others
- Important role of the child’s school
Study 4: Role of grandparent support

- Survey of 72 parents caring for primary school-aged children with disabilities 1-8 years.
- Changing demographics: grandparents working and living longer BUT
- Are still a primary source of support to mothers, especially the maternal grandmother
  - Mothers PD related to the health of the maternal grandmother
- Closeness of relationship between the mother and grandparents was related to levels of practical and emotional support
Implications for carer supports

- Increasing awareness of the impact of caring & challenges of combining paid work and care
- Workplace flexibility
  - Fair Work Act 2009/2013 “Right to Request” workplace legislation
- Flexibility of services and supports
  - Impact of the NDIS (individualised funding)
- Funding for respite; school supports
- Availability of carer specific support
Thank you!

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