

# 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

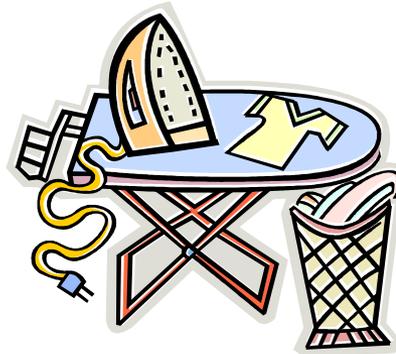
- ▶ Consequences of caring on the daily activities of parents of preschool aged children with developmental disabilities?
- ▶ Partnership with Disability SA
- ▶ Mixed methods
  - Semi-structured interviews (x 95)
  - Standardised questionnaires
  - 24 hour time use diaries

# Key outcomes (time use diaries)

Study parents spent:

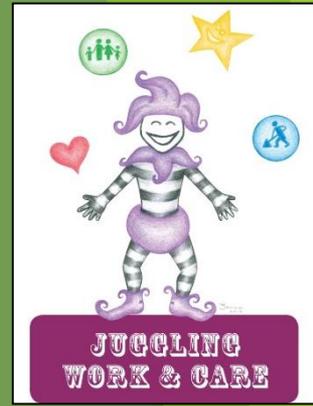
- ▶ Substantially more time in “active” care (physical care; emotional care; teaching/ helping/ reprimanding)
- ▶ Substantially less time in “passive care” (minding)
- ▶ The same amount of time more “qualitative” care activities such as playing/ reading/ talking to child

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

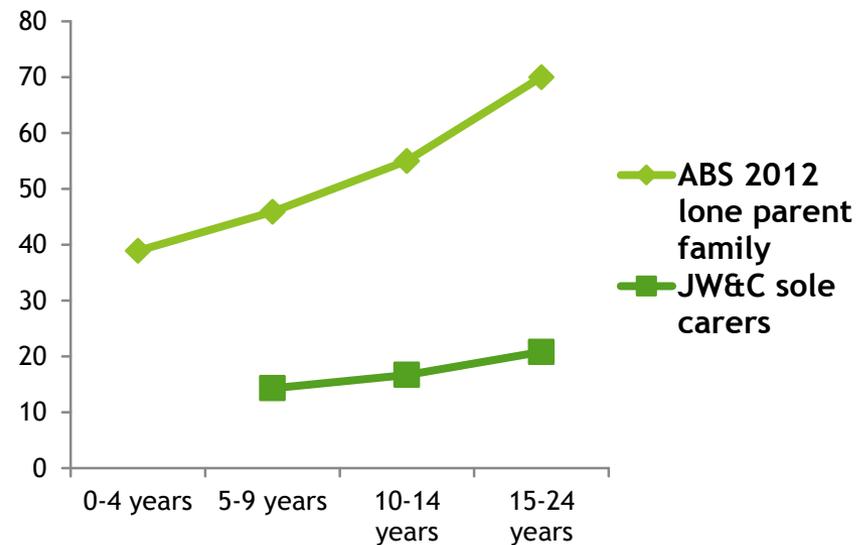
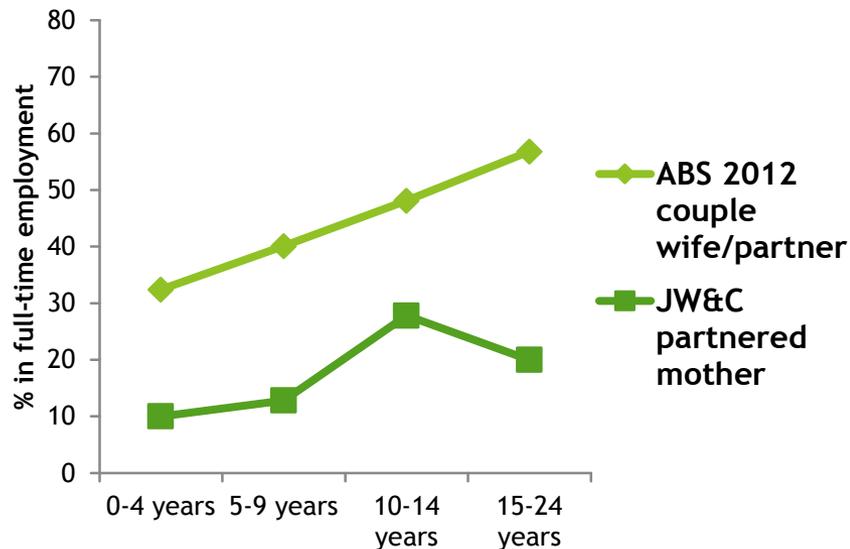


# Key outcomes:

## 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

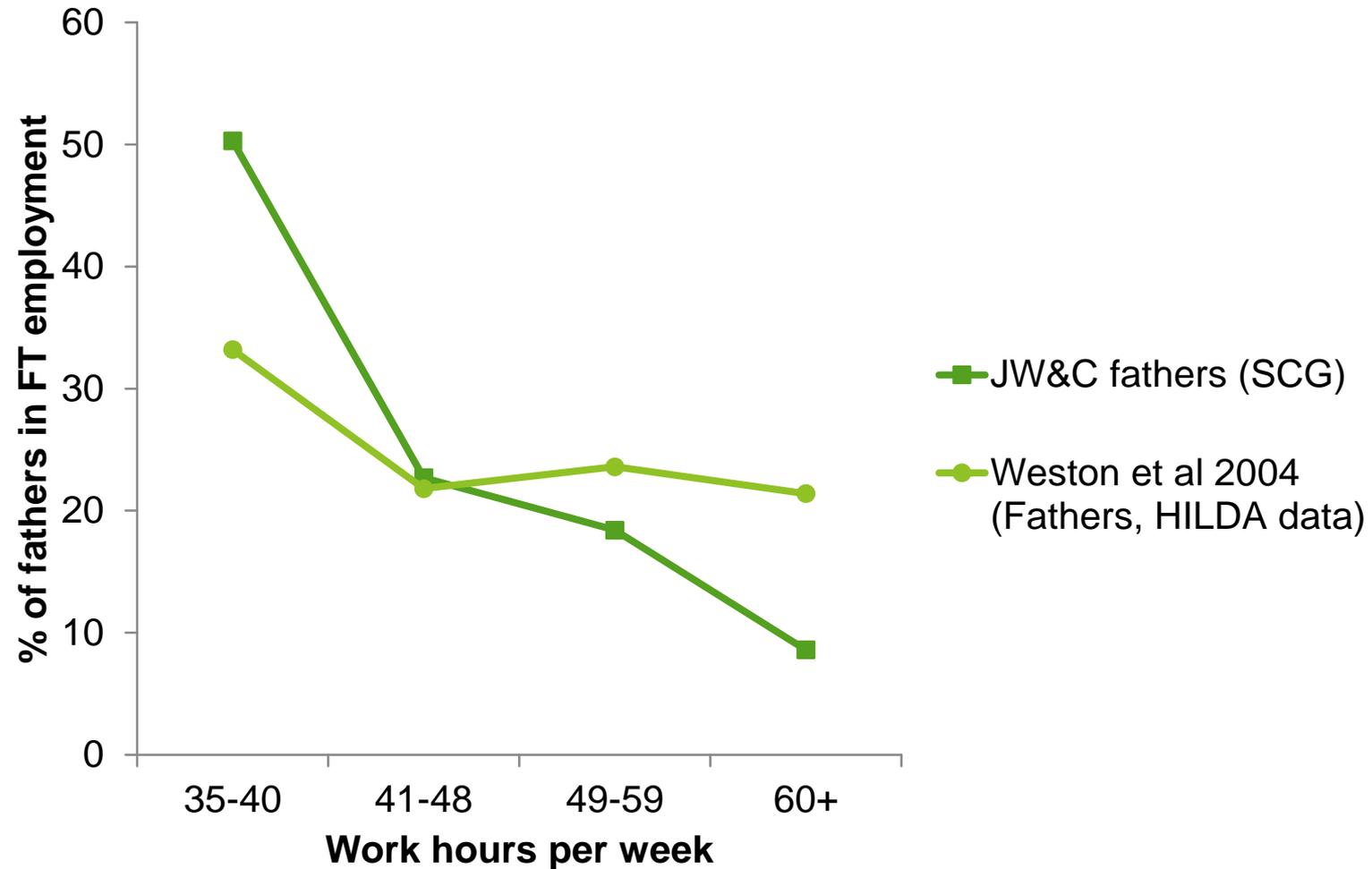


# Key outcomes:

## 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)



# 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:

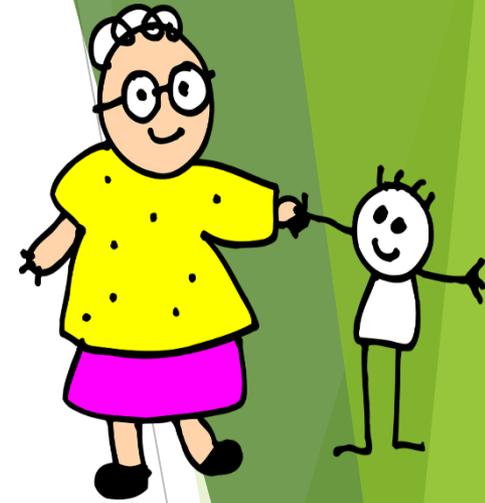
## Focus on sole mothers

- ▶ 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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# Published articles

- Sawyer, M., Bittman, M., LaGreca, A., Crettenden, A., Borojevic, N., Raghavendra, P., & Russo, R. (2011) Time demands of caring for children with cerebral palsy: What are the implications for maternal mental health. *Developmental Medicine and Child Neurology*, 53(4), 338-343.
- Sawyer, M., Bittman, M., La Greca, A., Crettenden, A., Harchak, T., & Martin, J. (2010). Time demands of caring for children with autism. What are the implications for maternal mental health? *Journal of Autism and Developmental Disorders*, 40(5), 620-628.
- Crettenden, A., Wright, A., & Skinner, N. (2014). Mothers caring for children and young people with developmental disabilities: Intent to work, patterns of participation in paid employment and the experience of workplace flexibility. *Community, Work and Family*, 17(3), 244-267
- Wright, A, Crettenden, A., & Skinner, N. (July 2016). Dad's care too! Participation in paid employment and experiences of workplace flexibility for Australian fathers caring for children and young people with disabilities. *Community, Work & Family*, 19(3), 340-361
- Cole, L., Crettenden, A., Roberts, R., & Wright, A. (2016). The experience of sole mothers balancing paid work with care for a child with a disability. *Australian Journal of Social Issues*, 51(3), 317-339.