

## RESEARCH FINDINGS: OUTCOMES 1

How does caring for children and young people  
with disabilities affect parents' workforce  
participation and experience of work?



This is the first of two brochures describing outcomes of the Juggling Work & Care study, carried out by Novita Children's Services (Novita) with the Centre for Work + Life at the University of South Australia, and South Australian Disability Services. The study was funded by the Channel 7 Children's Research Foundation.

This brochure focuses on work participation and experiences of parents caring for children with disabilities. Results are presented for mothers and fathers in couple families and for sole carers.

## Background research

In Australia, children and young people with disabilities are most commonly cared for by family members at home. This provides psychological and social benefits for children but has personal and financial consequences for parents and other caregivers. The overall value of unpaid care by parents and other carers has been estimated to be greater than total government expenditure on all welfare services (AIHW, 2007).

Unpaid care responsibilities significantly impact on individuals' ability to work. Many years out of the workforce or earning a reduced income through part-time hours results in daily financial strain, little opportunity for 'saving for a rainy day', and reduced superannuation contributions, affecting carers' retirement plans.

Mothers are often the primary carer of their child with disabilities and are most likely to alter plans to return to work and change career pathways, potentially for as long as the child remains cared for at home.

Fathers also experience additional demands on their time and may change work patterns or status to accommodate their caring responsibilities. This can lead to increased financial pressure and difficulties achieving work-life balance.

Carers of people with disabilities in South Australia are the least likely in the nation to take part in paid employment. Little is known about how South Australian parents/carers of children with disabilities balance work and care responsibilities and whether this changes with age of child, diagnosis, or marital status of the caregiver.

## The Juggling Work & Care study

The Juggling Work & Care study took place in 2012. The study aimed to fill gaps in knowledge of ways in which caring for a child with disabilities affects workforce participation, work-care balance, and psychological well being of parents/carers. Results were intended to guide policy in the area of workplace and other supports for parents of children with disabilities, and to direct future research.

The study involved a paper-based and online survey that was sent to 1309 families of clients of Novita and Disability Services, aged 0 to 25 years of age.

Four hundred and sixteen surveys were received from primary caregivers (mostly mothers), and 235 surveys were received from secondary caregivers (mostly fathers). Families ranged across the socioeconomic spectrum and included children with many different diagnoses and disabilities.

Within couple families, results focus on mothers who reported they had primary caregiving responsibilities for their child with disabilities ('partnered mothers') and fathers who had secondary caregiving responsibilities. Sole carers included mothers (87%), fathers (7%), and other relatives (6%).

The enthusiastic response to the Juggling Work and Care study reflects how important these issues are to parents and carers of children with disabilities.

1

KEY FINDING

# Main outcomes of the Juggling Work & Care study

## Plans to return to work

Over a quarter (29%) of partnered mothers and almost half (48%) of sole carers in the Juggling Work & Care study who had intended to return to work after the birth of their child were not in paid employment at the time of the study. The majority said their caring responsibilities were the reason they felt unable to work.

Of the group who stated they had not intended to return to work after the birth of their child, one in five indicated they were in paid employment. Most said the financial strain of caring for their child with disabilities was their reason for returning to work.

Caring for children with disabilities significantly impacts parental plans to return to and remain in the workforce.

2

KEY FINDING

## Participation in paid employment

At the time of the study, 62% of partnered mothers were in paid employment, similar to rates for mothers in the general population (65%; Australian Bureau of Statistics (ABS), 2013).

Only 44% of sole carers in the Juggling Work & Care study were in paid employment at the time of the study, compared to 57% of lone parent families in the general population (ABS, 2013).

Fewer sole carers of children with disabilities were in paid employment than those in the general population.

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KEY FINDING

Partnered mothers and sole carers who were in paid employment had children with less severe disabilities than those who were not in paid employment.

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KEY FINDING

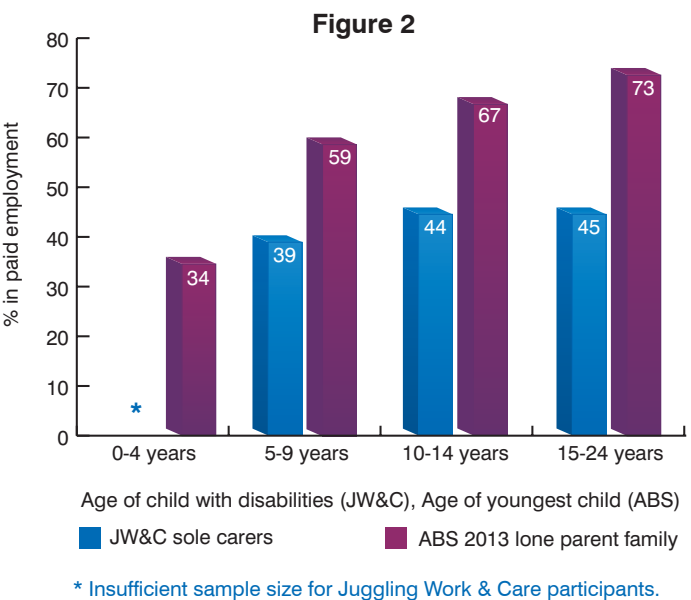
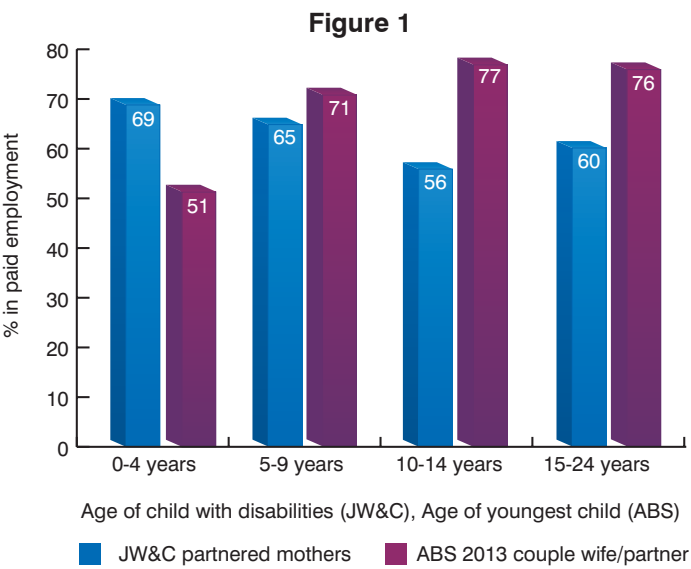
For partnered mothers, participation in paid employment did not increase with age of the child. This is in marked contrast to the substantial increase in maternal employment participation in the general population as the child gets older (Figure 1).

Participation in paid employment for sole carers showed only a small increase as the age of the child increased, in contrast to the large increase observed in lone parent families in the general population (Figure 2).

Partnered mothers and sole carers do not return to work as the child with disabilities gets older.

5

KEY FINDING



Most fathers (90%) who were the secondary caregiver for their children with disabilities were in paid employment, similar to fathers in the general population (89%; ABS, 2013).

## Hours of work

Only 19% of partnered mothers and sole carers in paid employment worked full-time hours (35 or more hours per week). In the general population, 43% of employed mothers and 54% of lone parents work full-time (ABS, 2013).

Partnered mothers and sole carers had only a small rise in full-time employment participation as the age of the child increased, very different to the steady increase in employment for these groups in the general population (Figures 3 and 4).

Figure 3

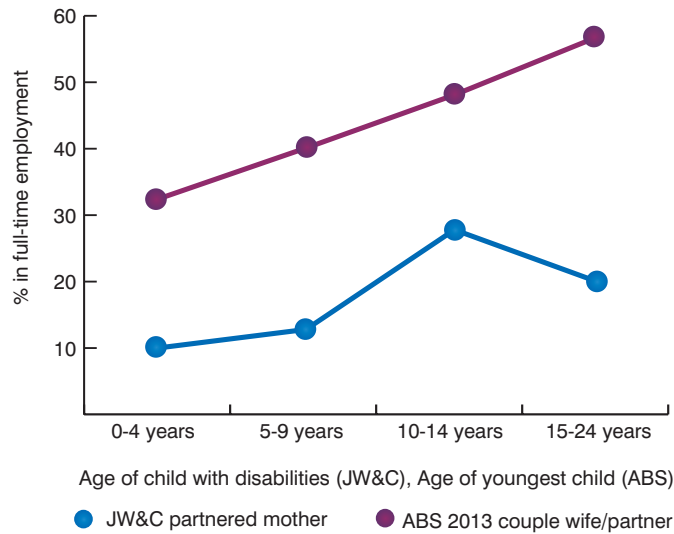
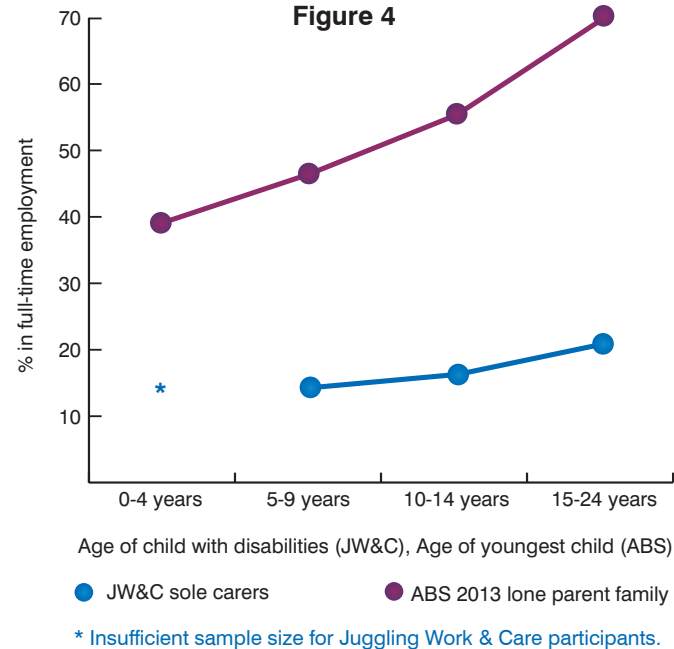


Figure 4



Partnered mothers reported a range of impacts:

1. Working part-time to fit in care responsibilities
2. Unable to take promotions or take on higher level work due to working part-time
3. Limited job opportunities due to the need for increased workplace flexibility
4. Emotional and physical stress which can impact on work performance
5. Unable to take on study or professional development activities
6. Financial strain as a result of reduced hours.

*"I've had to forgo higher duties and advancing to higher levels as I could only work part-time. My career has suffered."*

*"[It's] extremely difficult to find a job where you can leave at a moment's notice and have many days off for appointments and sickness or child just not cooperating."*

*"Sometimes I feel so overwhelmed with my child's issues that I find work hard to do."*

More than a quarter (28%) of partnered mothers working part-time reported they would like to work more hours than they do. In the general population, only 11% of partnered mothers said they wished to increase their work hours (Skinner et al., 2012).

Four in ten fathers (39%) in a secondary caregiver role for their children with disabilities reported that caring had impacted on their job opportunities or career progression.

Fathers indicated that caring had resulted in:

1. Reduced earning capacity and career opportunities
2. Negative impact on job performance
3. Staying in a job they don't like to retain job security
4. Altered work status, e.g. having to leave a senior position.

*"I have to think about my child with disability and family first. So I work less than I normally do."*

*"I am unable to maintain the hours required to secure a more senior position as I need to account for unforeseen illness and hospitalisation."*

**Partnered mothers and sole carers of children with disabilities are substantially less likely to work full-time than parents in the general population, regardless of age of child.**

6

KEY FINDING

**Fathers in a secondary caregiver role for children with disabilities work fewer hours per week than fathers in the general population.**

7

KEY FINDING

## Impact on work

Seven in ten partnered mothers (67%) and sole carers (73%) of children with disabilities felt that caring had impacted on their job opportunities or career progression. Those caring for children and young people with more severe disabilities and those working part-time had significantly more consequences from their caring responsibilities.

**Caring for children with disabilities impacts on job opportunities and career progression of parents and carers, particularly those who have children with more severe disabilities.**

8

KEY FINDING



## Financial implications of caring for children with disabilities

Over their working life, mothers caring for children with disabilities are likely to earn between a quarter and half the income of similar women in the general population (Nepal et al., 2009). In the Juggling Work & Care study, parents/carers who were not in paid employment or who worked part-time were further financially disadvantaged.

Partnered mothers and sole carers who were not in paid employment or who worked fewer hours had a lower family income than those who were in employment or who worked full-time.

9

KEY FINDING

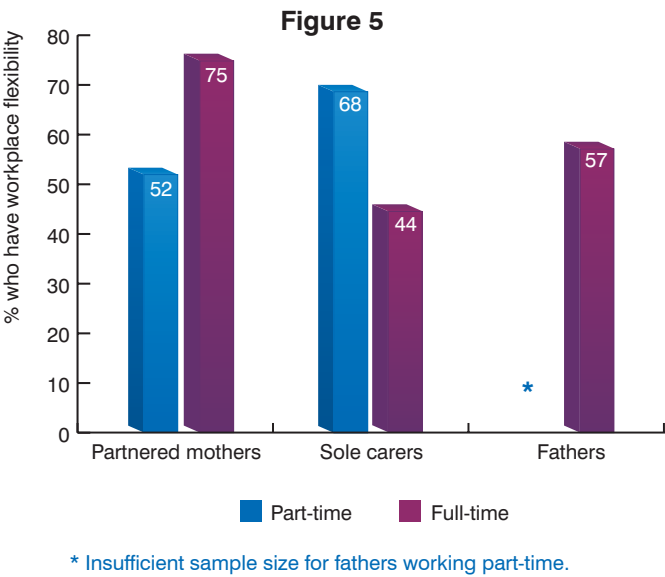
Two thirds of partnered mothers and almost all sole carers who were not in paid employment had gone without things their family really needed in the past year because they were short of money.

10

KEY FINDING

### Perceived flexibility at work

The percentage of employed parents/carers in the Juggling Work & Care study who believed they could access flexible working conditions to meet their caring responsibilities varied according to participant group and employment status (Figure 5).



Partnered mothers working part-time and sole carers working full-time were least likely to report access to flexible working conditions.

11

KEY FINDING

### Why carers of children with disabilities believe that flexibility is not an option:

1. Fixed hours of work
2. Inadequate workplace staffing (to accommodate changes to shifts or days of work)
3. Unavailability of suitable child care (for partnered mothers and sole carers only)

4. Lack of understanding in the workplace
5. Have to work to earn an income and fear of job loss.

*“My job is set school hours, 8.30am till 3pm.”*

*“If I don’t go to work I won’t be called in for a few days for having time off.”*

*“I am the sole sales person in this state. There is no back up. If something needs doing, I do it.”*

### What partnered mothers and sole carers thought could help:

1. Self-employment / casual contract / part-time employment
2. Flexibility of hours of work / days of work / ability to use leave entitlements flexibly
3. Additional leave entitlements
4. Ability to work from home / bring child to work.

*“Being in the casual pool provides me with the best flexibility. However, I don’t get paid if I don’t work, therefore it impacts on income.”*

*“I changed employer last year to allow me flexibility that I didn’t get from my previous employer, more than halving my income!”*

### What fathers thought could help:

1. Flexible working hours
2. Increased availability and access to carer’s leave or other leave
3. Ability to work from home
4. Self-employment.

*“To have an employer that understands my caring role and that I have to leave at the drop of a hat with no question.”*

### The ‘Right to Request’

From January 1 2010, as part of the Australian National Employment Standards, parents/carers of children under school age or children under 18 years old with a disability have the ‘right to request’ (RTR) a change in working arrangements to help them to care for their child. The employer has a duty to consider such requests ‘reasonably’. The Fair Work Amendment Bill 2013 extends the RTR to all carers of people with disabilities (amongst others).

Awareness of RTR legislation amongst parents/carers in the Juggling Work & Care study was low (8-13%), less than half that of mothers and fathers in the general population who have that right (25-34%; Skinner et al., 2012).

Nine in ten parents/carers of children with disabilities under 18 years old are unaware of their right to request a change in working arrangements.

12

KEY FINDING

# What can be done to support unpaid carers of children with disabilities in Australian workplaces?

National Disability Services Australia estimates that if 20% of Australian carers return to work, then the economic impact would add \$32 billion per annum to Australia's economy. There would also be financial and social benefits for families.

The Juggling Work & Care study found that one in five parents/carers of children with disabilities who were not in paid employment had intended to return to work after the birth of their child. More than a quarter of parents

and carers who were in part-time employment said they would like to work more hours, if supported to do so.

Helping carers to take part in paid employment requires cultural change at the levels of society and the workplace to advocate for shared responsibility for care, regardless of gender or role, and to increase awareness of the caring responsibilities that affect nearly two in five employees (Australian Human Rights Commission, 2013).

## Legislation & flexible work arrangements

- Flexible work arrangements encourage carers to remain in and re-enter employment, reducing ongoing risk of financial hardship.
- There is an urgent need for education through service providers, community groups, and workplaces to raise awareness of the 'right to request' (RTR) legislation.
- RTR legislation should be strengthened and extended so carers have a right of appeal if requests are denied.

## Leave arrangements

- Leave arrangements for carers need to be strengthened and expanded.
- On-going additional leave entitlements not restricted to the age of the child could help parents/carers remain in the workforce.
- Carer's leave entitlements should be flexible, easy to access with immediate effect, and have the possibility of being extended.

## Services

- Increased availability of good quality and accessible paid care, suitable for children (and adults) with disabilities can help parents/carers to return to or remain in the workforce.

## Workplace initiatives

- Workplaces should be encouraged to adopt a carer-friendly workforce strategy to benefit employees and employers.
- Workplace policies such as working additional hours to make up for time taken to attend appointments, home-based work, or flexible start and finish times help parents/carers to combine work and care.
- Managers and senior staff should lead by example, encouraging men and women in all roles to use flexible work arrangements to meet caring responsibilities.

Further information about the Juggling Work and Care study may be found at [www.novita.org.au/juggling](http://www.novita.org.au/juggling) or by contacting:

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