

Parent-related stress of male and female carers of adolescents with intellectual disabilities and carers of children within the general population: A cross-sectional comparison.

## **Abstract**

*Background* Carers of children with intellectual disability show high rates of parent-related stress and are at an increased risk for deleterious physical and mental health.

*Materials and Methods* This study investigated the relationship between demographic and social characteristics and parenting stress, within two different cross-sectional samples of carers: those who care for an adolescent with an intellectual disability and carers from a population based sample. Participants were 1152 carers from the Household Income and Labour Dynamic in Australia study and 284 carers of adolescents with intellectual disabilities from the Ask study. *Results and Conclusions* The results supported previous research suggesting carers of children with intellectual disabilities experience high parent-related stress. The results also support the buffer model of social support, as high social support was related to lower parent-related stress. Self-rated prosperity, financial pressure and relationship status were also related to lower levels of parent-related stress.

## **Introduction**

Parents of children with intellectual disabilities experience high levels of parent-related stress, that is, stress resulting from the demands of parenting (Baker et al., 2005, Hauser-Cram et al., 2001). Parent-related stress (sometimes called parenting stress) is distinct from parental stress, which is the overall stress level of parents and can result from stressors other than the child or parenting, e.g., financial problems, isolation. The effects of parent-related stress can be wide-reaching.

There is a strong association between stress, including parent-related stress, and increased risk of major depression (Hammen, 2005, Nurullah, 2013). Indeed, mothers and, to a lesser extent, fathers of persons with intellectual disability have been shown to experience higher than average levels of common mental health issues, such as depression and anxiety (Baker et al., 2003, Emerson et al., 2010, Families Special Interest Research Group of IASSIDD, 2014, Olsson and Hwang, 2001, Saloviita et al., 2003, Singer, 2006). It has also been proposed that parent-related stress may increase negative parenting behaviours, such as coercive and inconsistent parenting styles that could contribute to the development of emotional and behavioural difficulties in children (Hastings, 2002, Weitlauf et al., 2014). Further, children with intellectual disabilities have a three to fivefold increase in the likelihood of experiencing emotional or behavioural problems (Einfeld et al., 2011) and maladaptive behavioural problems are related to higher levels of parent-related stress and the stress-reaction, depression (Baker et al., 2003, Bourke-Taylor et al., 2012, Feldman et al., 2007, Hassall et al., 2005, Hastings, 2002, Hauser-Cram et al., 2001, Wolf et al., 1989). Thus there are indications of a bi-directional relationship between parent-related stress and poor emotional and behavioural outcomes in both parents of children with intellectual disabilities and the children themselves.

Parenting an adolescent with intellectual disabilities has received little attention in the literature to date. Parents in the general population experience significantly higher levels of stress during their child's adolescence due to parental role and identity changes, difficulties in discipline, adolescent mood disruptions, and increased adolescent autonomy (Burke et al., 2008, Small et al., 1988, Todd and Jones, 2005, Wiley and Berman, 2012). When the child has an intellectual disability there may also be increased difficulties in care demands, such as increased physical size from childhood and managing menstruation (Patton and Viner, 2009, Chou and Lu, 2012). Additionally, adolescence is often associated with a high risk of mental disorders. The parent-related stress associated with adolescent mental disorders may be increased when the child has an intellectual disability as risk of comorbid psychiatric disorders for people with intellectual disability has been found to be three to four times greater than the general population across the lifespan (Cormack et al., 2000, Einfeld et al., 2006, Emerson and Hatton, 2007, Masi, 1998, McIntyre et al., 2002, White et al., 2005). Therefore, it is arguable that parents of an adolescent with intellectual disabilities would experience increased parent-related stress and should therefore be considered separately to parents of younger children with intellectual disabilities.

A psycho-social stress and resilience model derived from the transactional theory of coping and stress (Lazarus and Folkman, 1984) has been used to explain the relationship between impacts of stressors associated with caring for a child with an intellectual disability on family well-being. Grant and Whittell (2000) used this model, which emphasises the cognitive appraisals people bring to situations and the secondary and consequent appraisals of the coping resources they can call upon to deal with their circumstances. They found that coping was differentiated according to sex, life stage and family structure. Additionally, Peer and Hillman's (2014) review identified coping style, social support, and optimism as crucial components in the development of resilience. However, both reviews prompt further

investigation into particular factors that could promote or detract from the development of resilience.

Families supporting a child with intellectual disability are significantly more likely to experience social isolation, poverty and the range of environmental adversities associated with poverty (Burton-Smith et al., 2009, Emerson, 2013, Emerson and Brigham, 2015, Griffith et al., 2012, Hubert, 2011, Johnson et al., 2006). This gives cause for concern as poverty has been linked to high levels of stress and low mental health (Kuruville and Jacob, 2007, Santiago et al., 2011, Saunders, 1998). Further, it has been proposed that social support acts as a buffer to stress - decreasing loneliness, facilitating coping, and having beneficial physiological effects that lead to increased health (Cohen, 2004, Segrin et al., 2012, Waite, 1995). The difference in parent-related stress levels and the resultant stress-reactions between parents of adolescents with intellectual disability and parents of typically developing adolescents could be explained at least in part, by this increased financial pressure and decreased social support.

The present study aimed to examine whether the increases in parent-related stress can be attributed to the burden of care associated with parenting an adolescent with intellectual disabilities or whether it is related to competing explanations such as increased social isolation and/or financial hardship. Parent-related stress of parents of children and adolescents with and without intellectual disability was compared, controlling for demographic variables and social support. We hypothesised that parents of adolescents with intellectual disability will be more likely to have high levels of parent-related stress than parents of children and adolescents without intellectual disability, and that this relationship will remain after controlling for demographic characteristics and level of social support.

## **Method**

### *Participants and Procedure*

In order to compare the parent-related stress and social support of carers of adolescents with intellectual disability against carers from a community sample, data were extracted from two surveys: the *Ask* Study and the Household Income and Labour Dynamic in Australia (HILDA). The *Ask* Study was a randomised trial investigating a combined educational and health intervention package for adolescents with intellectual disability (Lennox et al., 2012). To be eligible to participate, students needed an Education Queensland verified intellectual disability, and to attend a Special Education School or a Special Education Unit in a mainstream school in South-East Queensland. In 2009, caregivers of participants in the *Ask* trial completed a questionnaire that included measures of parent-related stress and social support taken from the HILDA to allow for direct comparison of outcomes.

The HILDA is a yearly household-panel study that began in 2001. It originally consisted of approximately 7,600 Australian households and 20,000 individuals who completed either a face-to-face or a telephone interview, and then were given a self-completion questionnaire after the interview (Wooden and Watson, 2007). Each year family members 15 years and older are invited to participate. In order to gain a cross-sectional comparison with the 2009 *Ask* data, the present study utilised the ninth wave of the HILDA (2009/2010), which had an overall response rate of 72.6% for the interviews. 86.6% of people interviewed returned the self-completion questionnaire (Melbourne Institute of Applied Economic and Social Research, 2010).

In both surveys participants with parenting responsibilities for at least one adolescent aged 17 years or under completed the parent-related stress measure. Only these participants were included in the present analysis. In the *Ask* sample this may not necessarily have been the adolescent with intellectual disability (who was aged 14 - 20 years at the time of the 2009 exit survey). Only carers who were responsible for at least one child between 14 and 20 years old were extracted from the community dataset.

### *Participant characteristics*

There were 1,152 participants from the community sample and 284 from *Ask* who met the eligibility criteria for this study. Table 1 details participant demographics. In the community sample, 672 (58.3%) of respondents were female compared with 248 (87.3%) female respondents in *Ask*. The median (25<sup>th</sup>,75<sup>th</sup> percentile) age was 46 (43, 50) years (range = 30 to 72) in the community sample compared with 46(42, 50) years (range = 32 to 68) in *Ask*. The cause of disability for 13.0% of children of *Ask* participants was Down syndrome, 59.2% had other known syndromes and for 27.8% the cause was unknown.

### *Measures*

#### *Demographic and social variables*

Demographic and social characteristic recorded were age, sex, relationship status, prosperity, financial pressure and social support. Relationship status was reported as partnered/not partnered. Prosperity and financial pressure were self-rated. Prosperity was assessed using the question “Given your current needs and financial responsibilities, how would you say you and your family are getting on?” and responses were recorded on a six-point Likert-type scale ranging from “prosperous” to “very poor”. Participants were divided into the categories lowest/middle/highest based on the 25<sup>th</sup> and 75<sup>th</sup> percentiles of responses from the community data. Financial pressure was derived from six items, each relating to some aspect of everyday life (e.g., paying rent, buying food) that the respondent had difficulty with due to a shortage of money. Internal consistency was acceptable,  $\alpha = 0.71$ . If a respondent reported having difficulty with any item they were categorised as having high financial pressure.

#### *Social Support*

The HILDA’s Index of Social Support was included as a measure of loneliness or level of social support and friendship. The index measures perceived social support, which not only

gives an indication of the available support to the individual but to what extent it is utilised (Schwarzer and Leppin, 1991). Higher scores indicate lower levels of social support. The scale consists of 10 items on a 7-point Likert-type scale (1 = ‘strongly disagree’; 7 = ‘strongly agree’), for example, “people don’t come to visit me as often as I’d like” and “I often feel very lonely.” The measure was used in the HILDA survey and comprises two scales by Henderson et al. (1978; first 7 items) and Marshall and Barnett (1993; last 3 items). Internal consistency was excellent,  $\alpha = 0.93$ . Scores for each item were totalled to create a combined social support value for each participant. Items 3, 6, 8, 9, and 10 were reverse scored. Participants were divided into low, middle and high social support based on the 25<sup>th</sup> and 75<sup>th</sup> percentiles of the social support score from the community data.

#### *Parent-related stress*

Parent-related stress was measured by a 4-item 7-point Likert-type scale (1 = ‘strongly disagree’; 7 = ‘strongly agree’). The measure is a component of the HILDA originally developed for the JOBS child outcomes study by Child Trend, Inc. (Hofferth et al., 1998).

The items are as follows:

1. Being a parent is harder than I thought it would be.
2. I often feel tired, worn out, or exhausted from meeting the needs of my children.
3. I feel trapped by my responsibilities as a parent.
4. I find that taking care of my child/children is much more work than pleasure.

Internal consistency approached acceptability,  $\alpha = 0.67$ . A composite score was calculated by adding the scores for each item. For analysis the total scores were divided into ‘highly stressed’ (top 10%) and ‘not highly stressed’ (bottom 90%). The cut-score was defined to be the highest score which at least 10% of the community sample fell above. In this sample overall scores ranged from 4 to 28, and participants scoring 20 points or greater were classified as being highly stressed.

### *Statistical Analysis*

Data are summarised as frequency (percentage). Due to the between-dataset imbalances in demographic and social characteristics, before any regression analyses were conducted we used propensity score matching to identify individual respondents with similar social and demographic characteristics (Rosenbaum and Rubin, 1985). Subsequent analyses were undertaken using only data from individuals identified as having sufficiently similar characteristics. First we estimated the propensity scores for each individual as the logit of the demographic and social variables age, sex, relationship status, prosperity, financial pressure and social support regressed against the binary outcome parental stress. Then, the propensity scores were used to match respondents from the *Ask* data set with respondents from the community data set. We matched each individual respondent from the *Ask* data set with the 10 individual respondents from the community data set who had the closest propensity scores. The balance of the variables was compared to ensure all variables had a post-matching standardised bias of less than 5%. Propensity matching and tests of balancing were undertaken using the PSMATCH2 and PSTEST programs (Leuvin and Sianesi, 2003) written for Stata statistical software (StataCorp, 2015). Weighted logistic regression models were used to investigate associations of interest. First univariable analyses were conducted. Then multivariable analyses, where all measured covariables were included in the model, were conducted. Each individual from the *Ask* data set had an analytic weight of 1. Individuals from the community data set had weights starting at 0, representing no matches with respondents from *Ask*, and increasing in increments of 0.1, where each weight of 0.1 represents a match with one individual.

### **Results**

#### *Comparison of participants in the community sample and Ask survey*

Table 1 shows that participants in the community sample and *Ask* studies differed significantly in all demographic and social characteristics. Participants in the *Ask* rated themselves as less prosperous, were more likely to be female, more financially pressured, less likely to be in a relationship, and reported lower social support compared to participants in the community sample. Before propensity matching, 140 (12.2%) of the community respondents reported higher parent-related stress compared to 78 (27.8%) of *Ask* participants. Propensity matching led to 536 community participants being matched to at least one *Ask* participant. The largest number of *Ask* participants any community sample participant was matched to was 26. After matching, 18.7% of the community respondents reported higher parent-related stress and caregivers from the *Ask* study were significantly more likely to be in the highly stressed group (Odds Ratio (OR)=1.68; 95% CI=1.20 – 2.35,  $p = 0.003$ ).

Insert Table 1 here

*The relationships between demographic and social variables and parent-related stress in the community sample versus the Ask*

The unadjusted and adjusted association between each variable and parent-related stress within the community and *Ask* datasets, using the matched data, are presented in Table 2. The size of the effect of each demographic and social characteristic on parent-related stress was similar for the community and *Ask* cohorts, except for age, sex, and relationship status. Age was significantly related to parent-related stress only for the community participants, with the strength of the relationship increasing as age decreased. After adjustment, the odds of community participants aged less than 40 years being in the highly stressed group were 3.61 times greater than the odds for older carers (95% CI=1.29 – 10.18). Sex and relationship status were significantly related to parent-related stress only for the *Ask* participants. After

adjustment, the odds of male *Ask* carers and *Ask* carers who were not in a relationship being in the highly stressed group compared with female carers and carers in a relationship were 0.46 and 0.59 respectively (95%CI=0.24 – 0.87 and 95%CI=0.38 – 0.93 respectively). Both *Ask* and community participants who had low social support were more likely to be in the highly stressed group by a factor of 4.76 and 4.61 respectively (95%CI=2.78 – 8.14 and 95%CI=1.98 – 10.74 respectively).

Insert Table 2 here

*Differences in the association between cohort membership and parent-related stress within each subgroup of the demographic and social variables.*

*Ask* carers were more likely to be stressed than community carers if they were female, in a relationship, were not highly prosperous, or had low financial pressure (see Table 3). Further, *Ask* caregivers were significantly more likely to be in the highly stressed group in both the 40-50 and 50+ age groups, and the magnitude of effect was similar for both age groups. For example the odds of caregivers in the *Ask* cohort older than 50 years being highly stressed were 3.55 times greater than the odds of older caregivers in the community cohort being highly stressed, after adjusting for the effects of potentially confounding variables (95%CI=1.28 – 9.82). The equivalent figure in the 40-50 year age group was 2.78 (95%CI: 1.79 – 4.33). *Ask* caregivers with low social support had odds of being highly stressed 2.18 times greater than community caregivers with low social support (95%CI=1.51 – 3.14), but there were no significant between-cohort differences for the high or middle social support groups.

Insert Table 3 here

## Discussion

Caregivers of adolescents with intellectual disabilities experience more parental stress than caregivers of typically developing adolescents. This association held within most subgroups of investigated social and demographic variables, and is consistent with previous literature (Baker et al., 2003, Fidler et al., 2000, Hauser-Cram et al., 2001). This finding indicates that caring for an adolescent with intellectual disability places the carer at risk of higher levels of parent-related stress.

The current study found that social support attenuated the relationship between caring for an adolescent with an intellectual disability and parent-related stress. The theory that social support moderates or buffers the impacts of stressors on wellbeing and stress has wide consensus in the literature (e.g., Cohen, 2004; Segrin et al., 2012; Waite, 1995; Peer & Hillman 2014). The current results are consistent with the theory of social support as a buffer to parent-related stress, as carers with higher social support were no more stressed than carers of typically developing children. Carers with high social support were also less likely to be highly stressed within both carer groups. This finding raises questions about the importance of the quality of this social support. While caregivers from the community sample were more likely to be highly stressed if they were not in a relationship, caregivers from the *Ask* study not in a relationship were less likely to be stressed. Grant and Whittell (2000) found single carers placed a strong emphasis on cognitive coping strategies and a heightened dependence on personal resources for managing things. The present study cannot make any inferences about this association as no measures of relationship quality were included in the analysis. Further, due to the cross-sectional study design, directional conclusions cannot be made. For example, it is possible that factors such as personality could influence the relationship between social support and stress.

Previous literature that incorporates the Social Identity Model has shown success in improving wellbeing in other cohorts (Haslam et al., 2009). The Social Identity Model postulates that we define ourselves through our group memberships. This can have positive and negative impacts on health and wellbeing depending on group characteristics and the variety of group memberships (Haslam et al., 2009). This theory may help to explain the impacts of decreased perceived social support on parenting stress, as socially isolated carers would have limited group memberships and they may begin to define themselves through the negative aspects of their predominant group (i.e., a carer of a child with an intellectual disability).

Male and female caregivers both experienced high parent-related stress compared with caregivers of typically developing children. The effect estimates for each sex stratum between the Ask study and community sample were stronger for males than females, although the estimate of the difference within females is more precise due to their greater sample size. As there are more female than male caregivers of children with intellectual disabilities, it is understandable that there has been a larger focus on maternal coping and stress in previous literature; however these results suggest both sexes experience parent-related stress. It is likely that males bring different coping strategies into play or it may as Grant and Whittell (2000) suggest reflect their usual status as secondary caregivers.

Among caregivers of typically developing children, older caregivers (aged 50 years and older) were less likely to be stressed than younger caregivers, whereas in the sample of caregivers of adolescents with intellectual disability, older caregivers (aged 40 years and older) were more likely to be highly stressed. A possible explanation for the difference in these results is that as caregivers of typically developing children age, their children are heading into adulthood and are more independent, thus reducing parenting responsibilities. However, caregivers of adolescents with intellectual disabilities face having to continue

caring for their child as well as planning for their child's future care. During later adolescence, all parents have to manage the transition of their child from school to work or non-school life, but this has been identified as one of the most stressful periods of parenting a child with an intellectual disability, comparable to the stress at the time of the initial diagnosis (Baxter et al., 1995). In many cases this period is associated with continued or increased care requirements, with some parents having to reduce or leave work in order to care for their child now that they do not attend school regularly (Foley et al., 2012). Finding suitable programs for young adults with an intellectual disability that will suit their personality and interests is also stressful and time-consuming, with a small number of programs on offer (Murray, 2007). There are disability services provided by government agencies, but these are often limited and difficult to access (Foley et al., 2012, Murray, 2007).

Caring for a child with intellectual disability had an even greater impact on parent-related stress experienced by caregivers self-reporting low financial stress than it did those who reported high financial stress. This is consistent with previous findings by Emerson (2003) and Hatton and Emerson (2009). Emerson (2003) found that mothers were distressed by increased child emotional and behavioural problems only if the family was not in circumstances of poverty or in a deprived neighbourhood. Hatton and Emerson (2009) found a similar moderating effect of socioeconomic status, where detrimental effects of increased child behavioural problems on maternal anxiety, depression, and self-reported poor health were stronger for mothers of higher socioeconomic status. The authors hypothesised that this effect could be due to the relative impact of child behavioural problems in families of different financial means, i.e., within financially poorer families there may be other factors such as poor diet or unemployment, that could affect maternal wellbeing, thus decreasing the relative impact of child behavioural problems (Hatton and Emerson, 2009). They also suggested the effect could be due to other environmental factors in financially poorer families

(e.g., increased spousal support due to unemployment) or different sociocultural expectations between different socioeconomic stratum (e.g., distress caused by the child not meeting higher behavioural demands in wealthier families; Hatton and Emerson, 2009). However, the mechanisms behind this effect remain unknown. Further investigation is required to determine the contributing factors to risk and to replicate the present findings, as this may help to identify areas of impact where support can be given to these families. One possible direction for future research would be to investigate whether increasing social connectedness in carers of adolescents with intellectual disability increases wellbeing.

### *Strengths and limitations*

A strength of the present study was the use of statistical techniques to match and analyse the relationships between caregivers with similar demographic backgrounds. This allowed the discrepant samples to be compared analytically. The direct comparison between the two groups is an important contribution to the literature, as previous studies have mainly investigated the outcome effects of being a caregiver for a child with an intellectual disability separately, without a population comparison. Another strength was the inclusion of male caregivers in the analysis, as there has been an imbalance in the literature with less attention being paid to impacts on fathers (Hauser-Cram et al., 2001, Families Special Interest Research Group of IASSIDD, 2014, Smith and Grzywacz, 2014).

The cross-sectional nature of the present study is a major limiting factor as causal associations cannot be examined. Previous literature proposes that the relationship between demographic variables such as financial status have a bi-directional relationship with intellectual disability: families with low socioeconomic status are more likely to include a family member with intellectual disability which can then lead to increased poverty due to factors such as costs of care and decreased income due to caring for child rather than working (Emerson, 2003, Emerson and Hatton, 2007). Therefore, while it is evident that the two

caregiver groups come from different populations, no causal links can be made as to whether the differences in social and demographic variables preceded or were caused by having a child with intellectual disabilities. Finally, the measures of financial pressure and prosperity were carer-reported and may not provide a reliable account of financial status.

### *Conclusion*

Caregivers of adolescents with intellectual disabilities experience more parental stress than caregivers of typically developing adolescents; however this association was potentially buffered by high social support. It is suggested that this finding may be further investigated in relation to Social Identity Theory. While prosperity and not being in a relationship were associated with *Ask* caregivers being less likely to be highly stressed, these caregivers were still more stressed than community caregivers overall. Older caregivers of adolescents with an intellectual disability were more likely to be stressed than similarly aged caregivers of typically developing adolescents. The transition from childhood to adulthood of people with intellectual disabilities should be the topic of further research, as older caregivers of adolescents with intellectual disabilities were more stressed, whereas the opposite was found for caregivers of typically developing children. Families with a child with an intellectual disability who report low financial pressure showed higher parental stress, indicating a need for future research into the possible influencing factors in this relationship. The current findings begin to show the interactive nature of factors that influence wellbeing in carers of children and adolescent with intellectual disabilities. Several risk factors have been identified and future research should aim to further investigate the prospective impact of these factors, and the impact of interventions aiming to alleviate these factors.

**Table 1**

Demographic and social characteristics of participants in the community (HILDA) and *Ask* datasets. Characteristics presented as n(%) for unmatched data and as % for matched data. Propensity matching occurred at a 10:1 ratio; in total 536 unique community participants are represented in the matched sample.

		Community (unmatched) N=1552	Community (matched) <sup>a</sup>	<i>Ask</i> N=284
Sex	Female	672 (58.3%)	88.4%	248 (87.3%)
Age	> 50	250 (21.7%)	18.3%	66 (23.2%)
	40 – 50	775 (57.3%)	64.1%	178 (62.7%)
	<40	127 (11.0%)	17.6%	40 (14.1%)
Relationship status	In relationship	924 (80.2%)	71.1%	203 (71.5%)
Prosperity	Lowest	347 (30.1%)	50.0%	135 (47.5%)
	Middle	616 (53.5%)	44.1%	127 (44.7%)
	Highest	189 (16.4%)	5.9%	22 (7.8%)
Financial pressure	High	224 (19.4%)	36.4%	100 (35.2%)
Social Support	Highest	274 (23.4%)	14.4%	36 (13.0%)
	Middle	585 (50.8%)	38.5%	105 (37.9%)
	Lowest	293 (25.4%)	47.1%	136 (49.1%)
Parent-related Stress	High	140 (12.2%)	18.7%	78 (27.8%)

<sup>a</sup> Datasets were matched on all variables in the table except parent-related stress.

**Table 2**

The unadjusted and adjusted<sup>b</sup> relationships between each demographic and social characteristic and parent-related stress<sup>c</sup> for carers in the community (HILDA) and *Ask* cohorts.

		Community			<i>Ask</i>		
		Stress (%)	Unadjusted (95% CI)	Adjusted (95% CI)	Stress (%)	Unadjusted (95% CI)	Adjusted (95% CI)
Sex	Female	19.8%	1.00	1.00	29.0%	1.00	1.00
	Male	9.9%	0.44 (0.11 - 1.75)	0.22 (0.04 - 1.06)	19.4%	0.59 (0.28 - 1.26)	0.46* (0.24 - 0.87)
Age	>50	10.3%	1.00	1.00	28.1%	1.00	1.00
	40 – 50	18.4%	1.95 (0.67 – 5.73)	1.96 (0.72 – 5.29)	31.1%	1.15 (0.71 – 1.87)	1.54 (0.95 – 2.47)
	<40	28.3%	3.42* (1.11 -10.56)	3.61*(1.29–10.18)	12.5%	0.36 (0.13 – 1.06)	0.54 (0.23 – 1.30)
Relationship status	In relationship <sup>†</sup>	17.1%	1.00	1.00	28.0%	1.00	1.00
	Not in relationship	22.4%	1.40 (0.80 - 2.43)	0.88 (0.50 - 1.55)	27.2%	0.96 (0.61 - 1.51)	0.59* (0.38 - 0.93)
Prosperity	Lowest	22.4%	1.62 (0.91 – 2.88)	0.97 (0.55 – 1.71)	34.1%	1.55* (1.02 – 2.35)	1.26 (0.79 – 1.99)
	Middle+	15.2%	1.00	1.00	25.0%	1.00	1.00
	Highest	12.7%	0.82 (0.17 – 3.92)	1.89 (0.59 – 6.04)	4.6%	0.14 (0.01 – 4.04)	0.02 (0.00 – >1000)
Financial pressure	Low <sup>†</sup>	14.8%	1.00	1.00	27.1%	1.00	1.00
	High	25.4%	1.97* (1.15 – 3.38)	1.43 (0.82 – 2.50)	29.0%	1.10 (0.72 - 1.67)	0.78 (0.49 – 1.24)
Social support	Lowest	29.9%	4.18** (1.90 – 9.16)	4.61**(1.98–10.74)	45.6%	4.97** (2.84 – 8.69)	4.76** (2.78 – 8.14)
	Middle+	9.3%	1.00	1.00	14.4%	1.00	1.00
	Highest	7.1%	0.75 (0.14 – 4.11)	0.81 (0.15 – 4.22)	2.9%	0.18 (0.01 – 9.13)	0.06 (0.00 – 418.87)

<sup>b</sup> Adjusted analyses are adjusted for all variables listed in the table. <sup>c</sup> Outcome variable.

\* $p < .05$ , \*\* $p < .001$ , + Reference group.

Nagelkerke pseudo R-squared values for models: sex = 0.03, age = 0.03, relationship status = 0.03, prosperity = 0.04, financial pressure = 0.03, social support = 0.11.

**Table 3**

The impact of dataset<sup>+</sup> on parent-related stress<sup>d</sup> within each subgroup of carer social and demographic variables.

		Odds ratio for Dataset (Unadjusted)	95% CI		Odds ratio for Dataset (Adjusted) <sup>c</sup>	95% CI	
			Low	High		Low	High
Sex	Female	1.65**	1.17	2.33	2.03**	1.43	2.90
	Male	2.21	0.48	10.21	4.29	0.81	22.68
Age	>50	3.40*	1.13	10.25	3.55*	1.28	9.82
	40 – 50	2.00**	1.33	3.03	2.78**	1.79	4.33
	<40	0.36	0.12	1.08	0.53	0.22	1.31
Relationship status	In relationship	1.88**	1.24	2.85	2.42**	1.60	3.66
	Not in relationship	1.29	0.72	2.31	1.63	0.91	2.90
Prosperity	Lowest	1.79**	1.18	2.71	2.49**	1.60	3.88
	Middle	1.87*	1.05	3.31	1.92*	1.13	3.27
	Highest	0.33	0.01	12.54	0.02	0.00	>1000
Financial pressure	Low	2.14**	1.32	3.46	2.80**	1.74	4.52
	High	1.20	0.74	1.95	1.53	0.93	2.52
Social support	Lowest	1.97**	1.39	2.79	2.18**	1.51	3.14
	Middle	1.65	0.67	4.06	2.11	0.84	5.31
	Highest	0.38	0.01	25.76	0.16	0.00	>1000

<sup>c</sup> Adjusted analyses are adjusted for all variables list in the table. <sup>d</sup> Outcome variable.

<sup>+</sup> Reference group = community (HILDA), \* $p < .05$ , \*\* $p < .001$ .

## References

- Baker B. L., Blacher J. & Olsson M. B. (2005) Preschool children with and without developmental delay: behaviour problems, parents' optimism and well-being. *J Intellect Disabil Res*, 49, 575-590.
- Baker B. L., McIntyre L. L., Blacher J., Crnic K., Edelbrock C. & Low C. (2003) Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217 - 230.
- Baxter C., Cummins R. A. & Polak S. (1995) A Longitudinal Study of Parental Stress and Support: From Diagnosis of Disability to Leaving School. *International Journal of Disability, Development and Education*, 42, 125-136.
- Bourke-Taylor H., Pallant J. F., Law M. & Howie L. (2012) Predicting mental health among mothers of school-aged children with developmental disabilities: the relative contribution of child, maternal and environmental factors. *Res Dev Disabil*, 33, 1732-1740.
- Burke J. D., Pardini D. A. & Loeber R. (2008) Reciprocal relationships between parenting behavior and disruptive psychopathology from childhood through adolescence. *J Abnorm Child Psychol*, 36, 679-692.
- Burton-Smith R., McVilly K. R., Yazbeck M., Parmenter T. R. & Tsutsui T. (2009) Quality of life of Australian family carers: Implications for research, policy, and practice. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 189-198.
- Chou Y. C. & Lu Z. Y. (2012) Caring for a daughter with intellectual disabilities in managing menstruation: a mother's perspective. *J Intellect Dev Disabil*, 37, 1-10.
- Cohen S. (2004) Social relationships and health. *The American Psychologist*, 59, 676-684.

- Cormack K. F., Brown A. C. & Hastings R. P. (2000) Behavioural and emotional difficulties in students attending schools for children and adolescents with severe intellectual disability. *Journal of Intellectual Disability Research*, 44, 124-129.
- Einfeld S. L., Ellis L. A. & Emerson E. (2011) Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. *J Intellect Dev Disabil*, 36, 137-143.
- Einfeld S. L., Piccinin A. M., Mackinnon A., Hofer S. M., Taffe J., Gray K. M., Bontempo D. E., Hoffman L. R., Parmenter T. & Tonge B. J. (2006) Psychopathology in young people. *The Journal of the American Medical Association*, 296, 1981-1989.
- Emerson E. (2003) Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47, 385-399.
- Emerson E. (2013) Commentary: Childhood exposure to environmental adversity and the well-being of people with intellectual disabilities. *J Intellect Disabil Res*, 57, 589-600.
- Emerson E. & Brigham P. (2015) Exposure of children with developmental delay to social determinants of poor health: cross-sectional case record review study. *Child Care Health Dev*, 41, 249-257.
- Emerson E. & Hatton C. (2007) Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication. *J Intellect Disabil Res*, 51, 866-874.
- Feldman M., McDonald L., Serbin L., Stack D., Secco M. L. & Yu C. T. (2007) Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *J Intellect Disabil Res*, 51, 606-619.

- Fidler D. J., Hodapp R. M. & Dykens E. M. (2000) Stress in Families of Young Children with Down Syndrome, Williams Syndrome, and Smith-Magenis Syndrome. *Early Education & Development*, 11, 395-406.
- Foley K. R., Dyke P., Girdler S., Bourke J. & Leonard H. (2012) Young adults with intellectual disability transitioning from school to post-school: a literature review framed within the ICF. *Disabil Rehabil*, 34, 1747-1764.
- Grant G. & Whittell B. (2000) Differentiated Coping Strategies in Families with Children or Adults with Intellectual Disabilities: the Relevance of Gender, Family Composition and the Life Span. *Journal of Applied Research in Intellectual Disabilities*, 13, 256-275.
- Griffith G. M., Totsika V., Nash S., Jones R. S. & Hastings R. P. (2012) "We are all there silently coping." The hidden experiences of parents of adults with Asperger syndrome. *J Intellect Dev Disabil*, 37, 237-247.
- Hammen C. (2005) Stress and depression. *Annu Rev Clin Psychol*, 1, 293-319.
- Haslam S. A., Jetten J., Postmes T. & Haslam C. (2009) Social Identity, Health and Well-Being: An Emerging Agenda for Applied Psychology. *Applied Psychology*, 58, 1-23.
- Hassall R., Rose J. & McDonald J. (2005) Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *J Intellect Disabil Res*, 49, 405-418.
- Hastings R. P. (2002) Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability*, 27, 149-160.
- Hatton C. & Emerson E. (2009) Does socioeconomic position moderate the impact of child behaviour problems on maternal health in South Asian families with a child with intellectual disabilities? *J Intellect Dev Disabil*, 34, 10-16.

- Hauser-Cram P., Warfield M. E., Shonkoff J. P., Krauss M. W., Sayer A., Upshur C. C. & Hodapp R. M. (2001) Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development*, 66, i-viii+1-126.
- Henderson S. D.-J., Paul; McAuley, Helen; Ritchie, Karen (1978) The patient's primary group. *British Journal of Psychiatry*, 132, 78-86.
- Hofferth S., Davis-Kean P. E., Davis J. & Finkelstein J. (1998) *The child development supplement to the panel study of income dynamics: 1997 user guide*, University of Michigan, Institute for Social Research.
- Hubert J. (2011) 'My heart is always where he is'. Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home. *British Journal of Learning Disabilities*, 39, 216-224.
- Families Special Interest Research Group of IASSIDD (2014) Families supporting a child with intellectual or developmental disabilities: The current state of knowledge. *Journal of Applied Research in Intellectual Disabilities*, 27, 420 - 430.
- Johnson R. F., O'Reilly M. & Vostanis P. (2006) Caring for children with learning disabilities who present problem behaviours: a maternal perspective. *J Child Health Care*, 10, 188-198.
- Kuruvilla A. & Jacob K. S. (2007) Poverty, social stress & mental health. *The Indian Journal of Medical Research*, 126, 273-278.
- Lazarus R. S. & Folkman S. (1984) *Stress, appraisal, and coping*, Springer, New York.
- Lennox N., Ware R., Carrington S., O'Callaghan M., Williams G., McPherson L. & Bain C. (2012) Ask: a health advocacy program for adolescents with an intellectual disability: a cluster randomised controlled trial. *BMC Public Health*, 12, 750.

- Leuvin E. & Sianesi B. (2003) *PSMATCH2: Stata module to perform full Mahalanobis and propensity score matching, common support graphing, and covariate imbalance testing.* , Boston College Department of Economics, Boston, MA.
- Marshall M. L. & Barnett R. C. (1993) Work family strains and gains among two-earner couples. *Journal of Community Psychology*, 21, 64-78.
- Masi G. (1998) Psychiatric illness in mentally retarded adolescents: Clinical features. *Adolescence*, 33, 425-434.
- McIntyre L. L., Blacher J. & Baker B. L. (2002) Behaviour/mental health problems in young adults with intellectual disability: The impact on families. *Journal of Intellectual Disability Research*, 46, 239-249.
- Melbourne Institute of Applied Economic and Social Research (2010) HILDA Survey Annual Report 2010 The University of Melbourne, Melbourne.
- Murray S. (2007) Families' care work during the transition from school to post-school for children with severe disabilities. *Family Matters*, 76, 24-29.
- Nurullah A. S. (2013) "It's Really a Roller Coaster": Experience of Parenting Children with Developmental Disabilities. *Marriage & Family Review*, 49, 412-445.
- Olsson M. B. & Hwang C. P. (2001) Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 535-543.
- Patton G. C. & Viner R. M. (2009) Pubertal transitions in health. In: *Challenges in adolescent health: An Australian perspective.* (Ed. ^ (Eds. D. Bennet, S. Towns, E. Elliott & M. J). Nova Science Publishers, Inc, New York.
- Peer J. W. & Hillman S. B. (2014) Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and

- recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 92-98.
- Rosenbaum P. R. & Rubin D. B. (1985) Constructing a control group using multivariate matched sampling methods that incorporate the propensity score. *The American Statistician*, 39, 33-38.
- Saloviita T., Itälänmäki M. & Leinonen E. (2003) Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model. *Journal of Intellectual Disability Research*, 47, 300-312.
- Santiago C. D., Wadsworth M. E. & Stump J. (2011) Socioeconomic status, neighborhood disadvantage, and poverty-related stress: Prospective effects on psychological syndromes among diverse low-income families. *Journal of Economic Psychology*, 32, 218-230.
- Saunders P. (1998) Poverty and health: Exploring the links between financial stress and emotional stress in Australia. *Australian and New Zealand Journal of Public Health*, 22, 11-16.
- Schwarzer R. & Leppin A. (1991) Social Support and Health: A Theoretical and Empirical Overview. *Journal of Social and Personal Relationships*, 8, 99-127.
- Segrin C., Burke T. J. & Dunivan M. (2012) Loneliness and poor health within families. *Journal of Social and Personal Relationships*, 29, 597-611.
- Singer G. H. S. (2006) Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation*, 111, 155-169.
- Small S. A., Eastman G. & Cornelius S. (1988) Adolescent autonomy and parental stress. *Journal of Youth and Adolescence*, 17, 377-391.

- Smith A. M. & Grzywacz J. G. (2014) Health and well-being in midlife parents of children with special health needs. *Fam Syst Health*, 32, 303-312.
- StataCorp (2015) Stata Statistical Software: Release 14. StataCorp LP, College Station, TX.
- Todd S. & Jones S. (2005) Looking at the future and seeing the past: The challenge of the middle years of parenting a child with intellectual disabilities. *Journal of Intellectual Disability Research*, 49, 389-404.
- Waite L. J. (1995) Does marriage matter? *Demography*, 32, 483-507.
- Weitlauf A. S., Vehorn A. C., Taylor J. L. & Warren Z. E. (2014) Relationship satisfaction, parenting stress, and depression in mothers of children with autism. *Autism*, 18, 194-198.
- White P., Chant D., Edwards N., Townsend C. & Waghorn G. (2005) Prevalence of intellectual disability and comorbid mental illness in an Australian community sample. *Australian and New Zealand Journal of Psychiatry*, 39, 395-400.
- Wiley R. E. & Berman S. L. (2012) The relationships among caregiver and adolescent identity status, identity distress and psychological adjustment. *J Adolesc*, 35, 1203-1213.
- Wolf L. C., Noh S., Fisman S. N. & Speechley M. (1989) Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders*, 19, 157-166.
- Wooden M. & Watson N. (2007) The HILDA Survey and its Contribution to Economic and Social Research (So Far). *Economic Record*, 83, 208-231.