



## Use of equipment and respite services and caregiver health among Australian families living with Rett syndrome

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### ABSTRACT

This study assessed factors that could influence equipment and respite services use among Australian families caring for a girl/woman with Rett syndrome and examined relationships between use of these resources and the health of female caregivers. Data was sourced from questionnaires completed by families ( $n = 170$ ) contributing to the Australian Rett Syndrome Database in 2004 and 2006. Regression analysis was used to assess relationships between child factors (age, mobility, clinical severity and behaviour), family factors (accessibility and socio-economic factors) and the use of equipment and respite services in 2004, and relationships between resource use in 2004 and health of female caregivers as measured by the SF-12 in 2006. In 2004, the majority (88.3%) of families used at least one piece of equipment with more equipment use associated with greater mobility restrictions. Home respite services were used by 54.9% of families and overnight respite services by 47.6% of families. Use of more home respite services was associated with severely restricted levels of mobility and mothers having a vocational or university qualification. Use of more overnight respite services was associated with increasing age of the girl/woman with Rett syndrome and mothers being employed while use of less overnight respite services was associated with increasingly difficult behaviours in the girl/woman. In 2006, female caregivers had a mean mental health score of 41.1 (95% CI 38.9–43.3) and no relationships with previous resource use were identified. The mean physical health score of female caregivers was 48.7 (95% CI 46.8–50.5) and lower scores were associated with the use of equipment and overnight respite services. Equipment was a widely used resource whereas respite services, particularly overnight services, were used less widely. Further investigation of the reasons for this and alternative support strategies is indicated.

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## 1. Introduction

Rett syndrome is a rare neurodevelopmental disorder caused by a mutation on the methyl-CpG-binding protein 2 gene (*MECP2*) (Amir et al., 1999; Amir, Reid Sutton, & Van den Veyver, 2005). The disorder mainly affects females and results in severe physical and intellectual disability (Cass et al., 2003; Laurvick, De Klerk, et al., 2006). Features of Rett syndrome

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typically manifest following a period of apparently normal development in the first six months of life and include loss of purposeful hand use, communication skills, development of hand stereotypies, cognitive impairment, impaired mobility, and social withdrawal (Hagberg, Hanefeld, Percy, & Skjeldal, 2002). Care and management of girls and women with Rett syndrome is thus often complex with implications for resources use in day to day living (Moore et al., 2005) and maternal health over time (Laurvick, Msall, et al., 2006).

High levels of parental stress have been reported in Rett syndrome (Perry, Sarlo-McGarvey, & Factor, 1992) with mothers experiencing lower physical and mental health compared with a normative population (Laurvick, Msall, et al., 2006). Child behaviour (Bourke et al., 2008; Laurvick, Msall, et al., 2006), and severity (Bourke et al., 2008; Raina et al., 2005), family support (Guralnick, Hammond, Neville, & Connor, 2008), functioning (Raina et al., 2005), financial stress (Olsson & Hwang, 2008) and education level, maternal employment (Laurvick, Msall, et al., 2006), and the burden of caring (Raina et al., 2005) may all relate to levels of stress or health of parents of a child with a disability.

Families with a child with a disability often use adapted or specially designed equipment (Benedict & Baumgardner, 2009) which could potentially reduce the burden of care for caregivers by increasing children's functional performance and independence. Respite services provide the primary caregiver short-term relief from caring responsibilities (Chan & Sigafos, 2000; Damiani, Rosenbaum, Swinton, & Russell, 2004; Mac Donald, Fitzsimons, & Noonan Walsh, 2006; McGill, Papachristoforou, & Cooper, 2006; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Their use has been associated with decreases in stress and worry (Cowen & Reed, 2002; Ruble & McGrew, 2007). This study assessed factors that could influence use of equipment and respite services among Australian families caring for a girl/woman with Rett syndrome and examined relationships between use of these resources and later caregiver health.

## 2. Materials and methods

The Australian Rett Syndrome Database has collected longitudinal data about girls and women with Rett syndrome since its establishment in 1993 (Leonard, Bower, & English, 1997). Upon enrolment, questionnaires are administered to the child's paediatrician and family. Follow-up questionnaires have been distributed to participating families every 2 years since 2000 (Laurvick, Msall, et al., 2006) with piloting confirming that the content captured the range of complex issues that a person with Rett syndrome and their family experience. Questionnaire data collected in 2004 were used to ascertain child (age, mobility, behaviour and severity) and family (accessibility to services and socio-economic status) factors, and the use of equipment and respite services. This questionnaire was mailed out to 226 families and careworkers looking after a child or adult with a diagnosis of Rett syndrome with a response of 89.4% (202/226). For this study data provided by the 170 families was used. Families ( $n = 119$ ) where the female caregiver (natural mother, foster mother or grandmother) had completed the SF-12<sup>®</sup> Health Survey (Version 1.0) (Ware, Kosinski, & Keller, 1996) in the 2006 follow-up questionnaire were also used in the final analysis. The following measures were included.

### 2.1. Measurement of child factors

The mobility status of the person with Rett syndrome was categorised as normal or mildly restricted, severely restricted in comparison to other girls her age, able to support weight briefly during transfers, or totally dependent on a carer.

The Rett syndrome behaviour questionnaire (RSBQ) (Mount, Charman, Hastings, Reilly, & Cass, 2002) is a 40-item measure scored on a three-point scale with increasing scores indicating a greater presence of behaviours. The internal consistency of the total and each subscale score as well as test retest reliability has been found to be satisfactory (Mount et al., 2002). The "general mood" and "night behaviours" subscales were used in this analysis.

The Kerr scale (Kerr et al., 2001) was used to measure clinical severity. The scale contains 20 items, each describing a common feature of Rett syndrome. Items are scored according to severity, with increasing scores indicating greater clinical severity. A modified Kerr score was calculated for this study using 16 items (Colvin et al., 2003).

### 2.2. Measurement of family factors

The Accessibility/Remoteness Index of Australia (ARIA+) was used to measure families' accessibility to services as reflected by residential location. Based on road distances to service centers, the ARIA+ categorises residential location as either major city of Australia, inner regional Australia, outer regional Australia, remote Australia or very remote Australia (Glover & Tennant, 2003).

The Socio-Economic Indexes for Area (SEIFA) Index of Relative Disadvantage and the SEIFA Index of Education and Occupation were used to measure aspects of socio-economic status. SEIFA Indices are assigned to Australian geographical areas not individuals and provide a general measure of disadvantage and education and occupation (Pink, 2008).

The Australian and New Zealand Standard Classification of Occupations (ANZSCO) was used to measure the occupations of both parents. ANZSCO assigns occupations to one of five skill levels. Skill levels refer to the level of skill typically required to competently perform the tasks of a particular occupation and range from the highest skill level of 1 to the lowest skill level of 5 (Trewin & Pink, 2006).

Additional factors included the number of children in the family, family income, the education level of parents and their working status as also shown in Table 1.

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