



## Grandparent support of mothers caring for a child with a disability: Impacts for maternal mental health



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### ARTICLE INFO

#### Keywords:

Australia  
Mothers  
Carers  
Children with disability  
Mental health  
Grandparents

### ABSTRACT

**Background and aims:** Mothers who are primary carers of children with disabilities experience more mental health problems than mothers of typically developing children. We aimed to update and extend research into mothers' perceptions of grandparent support with care, and impacts for maternal psychological well-being, because although contemporary grandparents live longer they also work longer.

**Methods:** Surveys were completed by 72 mothers of clients (aged  $\leq 8$  years) of an Australian non-government disability agency. Mothers reported levels of practical and emotional support, face-to-face contact, and affectional solidarity with maternal and paternal grandparents. The Kessler Psychological Distress Scale (K10) was the dependent variable.

**Results:** Mothers indicated high to very high levels of psychological distress. As in previous comparable surveys, most support was offered by maternal grandmothers who had more contact and closest relationships with mothers. Maternal distress was related to maternal grandmothers' health and relationships with maternal grandfathers. Face-to-face contact and closeness of relationships were strongly linked to provision of support.

**Conclusions and implications:** Grandparents are important supports for mothers of children with disabilities: mothers lacking support from their own parents are particularly vulnerable. Clinicians should actively facilitate grandparent involvement, and promote extended family relationships.

### What this paper adds?

This study advances the small research literature exploring the role of contemporary grandparents in supporting the psychological well-being of mothers caring for young children with disabilities. This is especially important in context of demographic change, given consistent evidence that mothers of children with disabilities are at risk of mental health problems. If mothers are not well supported then the care of their children with disabilities is jeopardised. Although exploratory, the study uses a robust survey methodology and includes a well-validated outcome measure. Results update knowledge of grandparent support with care, and indicate key variables influencing provision of support – thus indirectly but substantially impacting on maternal psychological well-being. This information is essential for development of evidence-based recommendations to clinicians supporting families including children with disabilities. Specifically, either poor relationships with maternal grandfathers, or knowledge that the maternal grandmother is in poor health are risk factors for the mental health of mothers. Closeness of relationship between mothers and all grandparents is strongly related to the provision of practical and emotional support. It is important for clinicians to be mindful of the

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broader impacts of family relationships, provide family counselling if needed, and actively seek to involve grandparents in feedback and therapy sessions for young children with disabilities.

## 1. Introduction

### 1.1. Impacts of caring for a child with a disability

Caring for a child with disability is different from caring for a typically developing child. The term ‘exceptional caregiving responsibilities’ has been coined to provide a framework for considering the additional challenges and tasks required for caring for children with disabilities, over and above the caring involved in raising a typically developing, healthy child (Roundtree & Lynch, n.d.). The term reflects the need for more intense and prolonged caregiving, often requiring parents to acquire new skill sets and to become strong advocates for their child.

There is consistent evidence of the potentially adverse effects of caring on the psychological and physical health and wellbeing of family members (e.g., Edwards, Higgins, Gray, Zmijewski, & Kinston, 2008; Savage & Bailey, 2004; Schultz & Sherwood, 2008). More specifically, many studies show parents – in particular mothers who are most often primary caregivers – reporting more depressive symptoms and being at greater risk of clinical depression than parents of children without disabilities (Baily, Golden, & Ford, 2007; Gallagher & Hannigan, 2014; Resch, Elliot, & Benz, 2012; Singer, 2006).

### 1.2. Social support

Research examining the role of social support in the lives of parents of children with disabilities mirrors research looking at the role of social support in contributing to the health and well-being of other populations. In both sets of studies, there is evidence for the link between social support and psychological outcomes for individuals (e.g., Cohen & Wills, 1985; Dunst & Trivette, 1986; Guralnick, Hammond, Neville, & Conner, 2009; White & Hastings, 2004).

Cohen and Wills (1985) describe four commonly used types of support: esteem support, instrumental support, informational support, social companionship. The first two types of social support are particularly important for parents of children with disabilities. Esteem support, subsequently described as emotional support in this paper, includes supportive actions encouraging the recipient to feel esteemed, cared for and accepted. In the context of parenting, emotional support raises the parent’s self-esteem and provides confidence to undertake the parenting role (Andresen & Telleen, 1992). Instrumental support (also described as tangible, material or practical support) involves the provision of financial aid, material resources or needed services. Instrumental support, subsequently described as practical support in this paper, provides parents with the physical resources needed to cope with the demands of parenting, including behaviours that directly assist the parent such as helping with child care or housework (Andresen & Telleen, 1992).

### 1.3. Role of grandparents

Grandparents play a fundamental role in family life and can be a significant source of social support to parents, including those caring for a child with a disability (Baxter & Warren, 2015; Findler, 2000). Typically across all families grandmothers have more contact with their grandchildren than grandfathers, and maternal grandmothers have more contact than paternal grandmothers (e.g., Findler, 2000; Pollet, Nettle, & Nelissen, 2007; Reitzes & Mutran, 2004; Seligman, Goodwin, Paschal, Applegate, & Lehman, 1997).

Grandparents are often the first people parents approach for help or advice with parenting and other issues. They also assist by contributing practical assistance and financial support at crucial times (Mutchler & Baker, 2009). Many provide childcare for their grandchildren: unsurprisingly, they are the largest providers of informal childcare to families (ABS, 2014; Winefield & Air, 2010). However, in recent years there has been a general decline in the number of hours of childcare provided by grandparents (Jenkins, 2010). This may reflect societal and family changes including: higher rates of female employment, increased life expectancy, and changing attitudes – all leading to an evolution of the role of grandparents (Settles, 2014; Winefield & Air, 2010). Moreover grandparents may have multiple caring roles as members of “the sandwich generation”, supporting their own ageing parents, their partners, and adult children still at home in addition to grandchildren (Jenkins, 2010; Winefield & Air, 2010; Young & Denson, 2014).

### 1.4. Impact of grandparent support for parent well-being

Green’s (2001) research suggests grandparent participation in the care of children with disabilities contributes to parent well-being over and above other sources of support. In general, however, there has been little research examining grandparent involvement and support of care of children with disabilities, and even less which explicitly addresses the role of grandparent support on parent psychological functioning. For the most part, studies have been small scale and have used qualitative methodologies (Blacher, Knight, Kraener, & Feinfeld, 2016; Lee & Gardner, 2010; Mitchell, 2006; Rosenbaum, 2016; Trute, 2003). Research outcomes have, in some cases, been inconsistent. For example Sandler, Warren & Raver (1995) found a positive relationship between paternal adjustment and grandparent support. Hastings, Thomas and Delwiche (2002) however found grandparent support and conflict was only associated with maternal stress.

One early study undertaken by Baranowski and Schilmoeller (1999), involved a large scale survey of 150 mothers of children and young adults with disabilities about the support, helpfulness and involvement of both maternal and paternal grandparents. In this

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