**Executive Summary for PMG Research and Development Sub-Committee**

**Background**

Parent caregivers of physically disabled children have been identified as providing extra care beyond that expected of ‘the reasonable parent’ and subsequently being particularly vulnerable to stress (Raina et al 2005; Quittner et al 1992). For caregivers of children who use wheelchairs, there are the further environmental barriers to participation such as kerbs and doorways (Düger et al 2003), transportation, as well as the extra physical demands of moving and handling their child and equipment. For some parents caregiving can result in parents experiencing physical and or mental health problems, whilst others seem to gain huge satisfaction from this role. This study explored parents’ perceptions of the impact of caregiving for a child who uses a wheelchair, upon their physical, emotional, occupational health and wellbeing.

**Method**

A mixed methods approach was utilized to determine the parents’ perceptions. A battery of questionnaires and a semi-structured interview were completed with 10 parents. The questionnaires were collated, and the interviews were transcribed and analysed using phenomenological methods.

**Findings and Discussion**

Five main themes emerged: initial denial of the wheelchair, professional dependency, caregiver health and wellbeing, attitudes of others, and impact on siblings.

Specifically these parents reported experiencing ongoing physical & emotional stress balancing their time between the various demands and expectations; or spending considerable time following up on wheelchair delivery, maintenance or re-referral. They were generally sleep deprived and occupation limited, spending most of their time meeting their child’s needs. Although the majority of parents personally valued being able to care for their child, they subsequently struggled to accept external support services, to free them up to participate in activities of their own choice. They had unpredictable free time to re-establish relationships with friends, which meant they had a very limited social network for support and their own emotional wellbeing.

**Conclusion**

There is a need for early signposting and access to support services/ networks to help parents maintain good physical and emotional health. Efforts must also focus on exploring how parents can be supported in having a role outside of caregiving, even for short periods of time within the week. In addition, energy needs to continue to be directed at promoting inclusion and accessibility within the community for parent caregivers and their children.

**Key words**

Parent caregiver, physical and emotional wellbeing, wheelchair, activity balance, occupation