"TIME TO CARE": RELATIONSHIP BETWEEN TIME SPENT CARING FOR PRE-SCHOOL CHILDREN WITH DEVELOPMENTAL DELAYS AND PSYCHOLOGICAL, SOCIAL AND PHYSICAL WELL-BEING OF PARENTS.

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ABSTRACT

Advances in medical technologies and changing philosophies of health care have led to a rapid increase in home-based care for children with disabilities. While there are cost savings for health services if children are cared for at home there are extensive additional demands on the time and resources of parents, particularly primary caregivers, who are usually mothers. Previous studies have shown that parents caring for children with disabilities experience considerable stress and increased rates of mental health problems.

The present dissertation investigated the impact of caring on the daily lives of parents and in particular, a model proposing factors contributing to parental psychological, social and health outcomes. A preliminary qualitative study found time demands to be a core theme when discussing the consequences of caring, and when describing tasks of caring. A second, larger scale quantitative study focused on assessing the time constraints facing parents of children with developmental disabilities. Participants were 95 primary caregivers (mostly mothers) and 65 secondary caregivers (mostly fathers) of children (mean age = 4½ years) with developmental disabilities who were clients of the Early Childhood Service, part of Disability Services SA. Children's diagnoses included global developmental delay, Down syndrome, and autism. Caring and other activities of parents were assessed using a 24 hour pre-coded time-use diary. Parents also completed questionnaires measuring characteristics of child disability; their experience of time pressure and partner support; and psychological, social and physical well-being.

Examination of time-use diaries found parents of children with disabilities spent more time in "active" rather than "passive" caring tasks, than parents of children in the general community. As well, they spent less time in personal care, and less time in recreational activities. Intensity of caring, rather than total time caring was correlated with reports of daily stress for primary caregivers. Patterns of caring and non-caring activities carried out by primary caregivers on weekdays and weekend days differed from those undertaken by secondary caregivers, reflecting gender differences in parenting roles.

Analysis of questionnaire data showed children to have high levels of emotional and behavioural problems. Parents (particularly primary caregivers) had significantly poorer psychological, social and physical health outcomes than normative samples. Feelings of time pressure had a stronger association with parental depression than actual time spent caring. Further, testing of the model showed time pressure and partner support to be potential mechanisms by which caring for a child with a disability may lead to poor parental mental health. It is suggested that professionals providing early intervention services need a greater awareness of the constraints of the caring role undertaken by parents, together with the key role played by feelings of time pressure and partner support in contributing to the mental health of parents of children with disabilities.

DECLARATION

This thesis contains no material which has been accepted for the award of any other
degree or diploma in any university of other tertiary institution and, to the best of my
knowledge and belief, contains no material previously published or written by another
person, except where due reference has been made in the text.

I give consent to this copy of my thesis, when deposited in the University of Adelaide library, being made available in all forms of media, now of hereafter known.

Signed,

Angela D. Crettenden

Date:

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