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STORIES TO TELL:

FAMILIES OF CHILDREN WITH VISION IMPAIRMENT

A thesis submitted in partial fulfilment of the requirements
for the degree of
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at Massey University

Gwen Townsend Nagel

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ABSTRACT

This study explored the experiences of ten families of children with vision impairment. It gave emphasis to interactions within families and in relation to wider social, cultural and political contexts, highlighting the impact of medical, educational and social services and their policies on families.

Qualitative, collaborative methods offered techniques whereby ideas, feelings and beliefs ndividual to each family could be expressed within a climate of power sharing and reflection. Designed around a narrative, life history model, stories were accessed through the triangulation of focus group exploration, data sheet information and face-to-face family nterviews. Each story was treated as a unique, personal account, using participants own words as the authoritative statements on their experiences.

Findings were examined within the framework of Bronfenbrenner's (1979) Ecological Model. Issues relating to the educational and health needs of children predominated with educators the professionals parents most expected to support them. Parents sought parent-professional relationships which reflected equality, based on parent as well as professional expertise. Coping strategies used to negotiate both developmental tasks and social systems were identified, with the significance of alliances with other parents of children with disabilities highlighted. Advocacy was deemed to be a central process in bringing about change to social systems which were perceived as largely unchallenged by the great majority of parents.

Implications of the study were detailed in relation to families, professionals and service providers, policy development and future research. They underlined the importance of a society valuing diversity, and empowerment of people disadvantaged by prevailing attitudes, policies, structures and practices, providing a firm basis for actions that could enhance the lives of all families of children with disabilities.

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