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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
Master in Education (Guidance Studies)
at Massey University

Gwen Townsend Nagel

1996
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 individual 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 interviews. 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.
ACKNOWLEDGEMENTS

My sincere thanks and acknowledgements go to the following people:

The families of Dylan, Annie, Sarah, Andre, Shaun, Nuclelei, Toni, Hannah, Shaun and Richard who generously and thoughtfully participated in this study. The openness with which they gifted their personal stories has made the study possible. I am deeply grateful to them;

Sue Webb, Massey University, supervisor of this thesis, for her reflective, practical and supportive advice in the journey through the research process;

Marie Pollard for her wisdom, encouragement and ability to walk alongside;

Ray Murray, Trish O'Brien and colleagues and course members at Auckland College of Education, and Homai Vision Education Centre for their discernment, interest and support throughout;

Rebecca Williams and Owen Vickers for their assistance in the careful transcription of tapes; Rebecca Williams and Rod Wills for their skills in group graphics and photography; and Alan Kitcheman for his expertise in producing the pictorial montage of families; each gave their talents with generosity;

Bridget Lamphee for expertise and time generously given in the typing and formatting of the thesis;

The Royal New Zealand Foundation for the Blind, Homai Research and Development Committee, Auckland College of Education and Massey University for funding assistance which enabled the study to be carried out;

My family: Chris, Tim, David, Marcus and Stephen, for their love and support, and my family of origin whose experiences, in part, gave motivation for undertaking this study.
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