

**This is our life
This is our child**

**Mothers dancing in the
margins of disability**

Thesis submitted by

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B.Ed (Hons), Dip T (TCAE)

in November, 2003

for the degree of Doctor of Philosophy
in the School of Education
James Cook University

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A handwritten signature in black ink, reading "Natnael Anre Ypinazar". The signature is written in a cursive style with a large, decorative flourish at the end.

Saturday, 1 November 2003

Statement of Sources

Declaration

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education.

Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

A handwritten signature in black ink, reading "Naima Anre Ypinazar". The signature is written in a cursive style with a large, decorative flourish at the end.

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Statement on the Contribution of Others

In undertaking the research for this PhD thesis I have received financial support through being awarded an APA Scholarship. In addition, a student stipend from James Cook University of up to \$1000 has been made available.

Editorial and critical feedback has been provided by my supervisor, Dr Paul Pagliano and my co-supervisor, Dr. Kay Martinez. My husband, Dr Stephen Margolis has also provided editorial assistance.

Ethics approval for the research was granted by the Ethics Review Committee of James Cook University.

Acknowledgements

There are a number of people I would like to thank for their participation in the textual performance of this thesis. Not all were directly involved but without their support and understanding the task of research and writing would have been considerably more difficult.

My friend 'Serena' has offered ongoing encouragement and belief in the topic of the thesis and in my ability to tell the stories of the women. As before in my B.Ed (Hons) thesis I would like to acknowledge the support of my children Juanita and Justin who once again have spent holidays, evenings and weekends with their mother surrounded by interview transcripts, journal articles or at the computer. Steve, my husband, has offered continued support and provided input into the thesis, particularly in the area of medical discourse. He has spent many hours in conversation with me as I worked my way through the data analysis and writing of the thesis. Thank you for your ongoing encouragement to write this body of research.

My supervisor Dr Paul Pagliano has encouraged, critiqued and challenged me over the years this thesis took to come together as a choreographed textual piece. He has maintained a high level of interest, advice and commitment despite the difficulties encountered in completing this PhD at a distance. To Paul I owe a huge debt of gratitude for his time, energy and thorough and thoughtful responses to my early drafts. To my co-supervisor Dr Kay Martinez I thank you for your calm responses and also your time and commitment to my work as well as your willingness to work together as a team. Thank you both.

I thank the 15 women participants for your time, for the narratives you chose to (re)tell and for the gift of that (re)telling. It was my honour and privilege to have had the opportunity to listen to your stories.

This textual dance is dedicated to 'Norah' one of the participants who passed away during the writing of this thesis, and to 'Melanie' who passed away aged 11½ before the interviews commenced.

ABSTRACT

This study examines the narratives of 15 mothers who each have (or had) a child who is medically, educationally and socio-culturally constituted as having a disability. This research interrogates the mothers' narratives to consider motherhood from the discursive multiple position/ings of the society in which they live. The central research questions are: What are the lived experiences of these women who have a child who does not fit the dominant socio-cultural expectation of a 'normal' child? What subject positions are available for these women? How do they position themselves and how are they positioned in multiple discursive sites such as medicine and education?

By drawing on multiple methodological frames, the study explores the lived experiences and meanings as these mothers (re)construct the discourse of motherhood. Qualitative methods were used to design the research and gather data. Poststructural and feminist perspectives are added to provide additional methods of data analysis. Poststructuralist theorisings are considered new to the field of disability studies and hence provide an opportunity to re-examine subjectivity, power/knowledge and agency in fresh ways, as various mothers in this study reject, (re)construct and even rupture dominant non-disabled assumptions not only of disability, but also of motherhood.

The women's narratives transverse multiple discursive sites but particular attention is paid to medical and educational discourses and the complex interplay of relations of power constituted with/in these sites. The outcome of analysis suggests many women with a child with a disability actively take up the subject position of 'good mother' in keeping with the dominant discourse and ideology of motherhood available in Western society and (re)construct their lives as 'normal', while simultaneously encountering societal and attitudinal barriers which continue to marginalise their child named with a disability and by association, their families. Professionals can do much to dismantle barriers encountered by these mothers and work collaboratively to ensure inclusive life experiences are available. This thesis adds to the body of literature in disability studies by adding new forms of analysis of the interaction between the lived experiences of mothers and society, serving to challenge Western socio-cultural ways of 'knowing' about the intersection of motherhood and disability.

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