Travelling with two: balancing identity and risk in mothers with intellectual disability

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Statement of originality

I hereby certify that the work embodied in the thesis is my own work, conducted under normal supervision. I confirm that the thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution, with the exception of the approved partner university associated with this Doctoral Degree. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference has been made. I give consent to the final version of my thesis being made available worldwide when deposited in the University of Newcastle Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

Namira Williams

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*Pseudonyms

Abstract

Women with intellectual disability are a marginalised group who frequently have their children removed from their care. Whilst changes to policies for people with intellectual disability (ID) promote inclusion and a life comparable with that of their non-disabled peers, the opportunity to become parents and raise children is limited for these women. Few studies have considered the experiences of service providers during pregnancy for these women or the experiences of these mothers as they interact with the maternity system.

In this qualitative study, the aim was to understand and identify those barriers or enablers for mothers with intellectual disability during their childbearing period and for those providing care for them. A contemporary grounded theory research approach was taken to elicit the factors that contributed to better understanding the social processes occurring during mother–provider interactions. In-depth data were gained through semi-structured interviews with two mothers with intellectual disability and twelve service providers. Data were also drawn from eight focus groups with 33 service providers. Purposeful and theoretical sampling led to the recruitment of a range of service provider participants who comprised midwives, child and family nurses, a genetic counsellor, social workers, child protection staff, and disability support workers.

Findings contributed towards the conceptual theory of ‘Travelling with two’ in which women with intellectual disability, their significant others and service providers balance the concepts of risk and identity. Here, individual or professional identity is balanced against perceived risks as they are influenced by concepts of ‘good mothering’ and stigmatisation of those with intellectual disability. Three key processes contribute towards the core conceptual theory, as individuals assess, label and make decisions (making judgments) which contribute to how they engage, communicate, and collaborate. Significant to these processes is personal alignment to others or

organisations, and individual attributes which act to facilitate or inhibit navigating the maternity system. For women with intellectual disability, personal histories of stigmatised labels contributed to 'keeping in' and not identifying with intellectual disability. Consequently, this contributed to difficulties for many service providers, especially midwives, who lacked experience of identifying ID, and skills in making accommodations to assess, communicate and educate these mothers. When women with ID are judged as mothers using comparisons with mainstream women, child removal is often inevitable, occurring through covert processes with emotional trauma to all involved.

The findings from this study contribute to extant knowledge in better understanding the seen and unseen processes that occur during interactions between woman with ID and providers within the maternity system. Findings of this study provide qualitative evidence of gaps in current maternity service delivery for this marginalised group of mothers, with implications for policy development, provider education and focused models of maternity care.

Published conference abstracts

Williams, N., Taylor, A., Ebert, L., & O'Brien, L. (2015). Facilitating care for women with intellectual disability in pregnancy: A qualitative study into health professionals' understanding of the issues. *Women and Birth, 28*, S31. doi:https://doi.org/10.1016/j.wombi.2015.07.104

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List of Abbreviations

ACI Agency for Clinical Innovation (NSW Health)

ACM Australian College of Midwives

AIHW Australian Institute of Health and Welfare

AN antenatal

ANC antenatal clinic

AOC assumption of care

ACSQHC Australian Commission on Safety and Quality in Health Care

BW birth weight

CAFH child and family health

CALD culturally and linguistically diverse

CP child protection

COC continuity of care

EDS Edinburgh Depression Scale

FACS Family and Community Services

FG focus group

GP General Practitioner

GT grounded theory

ID intellectual disability

LBW low birth weight

LHD Local Health District

NDIS National Disability Insurance Scheme

NDS National Disability Service

NICE National Institute for Health and Care Excellence

NMBA Nursing and Midwifery Board of Australia

NSW New South Wales

PN postnatal

SW social worker

WHO World Health Organization

WWID women with intellectual disability