

**Challenges, Coping and Resilience in Caring for Children with
Disability Among Immigrant Parents:
A Mixed Methods Study**

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A thesis submitted in fulfilment of the requirements for the
degree of
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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. 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 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. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

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Ethar Alsharaydeh

Acknowledgement of Authorship

I hereby certify that the work embodied in this thesis contains published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written declaration endorsed in writing by my principal supervisor, attesting to my contribution to the joint publication/s/scholarly work.



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By signing below, I confirm that **Ethar Alsharaydeh** significantly contributed experimentally and intellectually to the publication entitled **Burdens, Challenges, Coping and Resilience in Caring for a Child with A Disability among Immigrant Parents: An integrative review**.



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- In 2018, I was awarded the Best HDR Poster Award for the school of Nursing and Midwifery, University of Newcastle. I won this award for my poster presentation at the HDR Research Week at the University of Newcastle, August 9, 2019, Newcastle, NSW: **Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A Cross Sectional Survey.**

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List of Abbreviations

The National Disability Insurance Agency (NDIA)

National Disability Insurance Scheme (NDIS)

Culturally and Linguistically Diverse (CALD)

Joanna Briggs Institute (JBI)

United States (US)

United Kingdom (UK)

Attention Deficit Hyperactivity Disease (ADHD)

New South Wales (NSW)

Zarit Burden Interview (ZBI)

Family Crisis Oriented Personal Evaluation Scales (F-COPES)

Connor-Davidson Resilience Scale (CD-RISC 10)

Participant Information Sheet (PIS)

Human Research Ethics Committee (HREC)

University of Newcastle (UON)

Standard Deviation (SD)

General Practitioner (GP)

Abstract

Parenting children with disability poses challenges and creates stress for parents, and this stress is compounded for immigrant parents who face additional challenges such as adjusting to a new environment and culture. The increase in the prevalence of childhood disability combined with an increased influx of immigrant families with diverse backgrounds in Australia indicates a need to improve childhood disability services for immigrant families. It is important to understand the challenges, coping and resilience of immigrant parents of children with disability and their experience in the caregiving role.

This study examines the challenges, coping strategies and resilience of immigrant parents raising children (0–18 years old) with disability. This study adopted a sequential explanatory mixed methods approach with two phases. The study was conducted in Australia from September 2018 to August 2019. The aim of the first phase of the study was to examine the challenges, coping and resilience of immigrant parents of children with disability. A quantitative cross-sectional survey was conducted involving 134 immigrant parents raising children with disability. The second phase of the study aimed to understand the challenges immigrant parents face and their experience in coping from parents' and service providers' perspectives. Qualitative, semi-structured, face-to-face interviews were conducted with nine immigrant parents and nine service providers. The results from the quantitative and qualitative phases were integrated into the final analysis.

The key findings of this study were:

- Immigrant parents experienced moderate to severe level of burden in raising children with disability due to challenges including overwhelming caretaking responsibilities, lack of supportive social networks, complexity of healthcare and

education system, language barrier, living in new culture, social isolation and feeling embarrassment over their children's behaviours.

- Immigrant parents used a variety of positive and proactive coping strategies including reframing, mobilising family to acquire and accept help from others, and seeking spiritual support to overcome their challenges. They had positive gains from parental experience.
- Immigrant parents had a reasonable level of resilience, with a higher level of resilience observed among immigrant parents who were employed, sought social connectedness, had English-language skills and had access to disability services.
- Immigrant parents who had higher a level of perceived challenges had a lower level of coping and resilience, while those with a higher level of resilience had higher level of coping.
- Perceived barriers to parental coping included barriers to establishing social networks and barriers to utilising available disability services. Services from competent service providers, availability of social support networks and steps taken to assert control over the situation were factors facilitating immigrant parents' coping.

Culturally appropriate and sensitive communication and care provided by healthcare professionals and service providers can facilitate service utilisation and reduce perceived stigma over children with disability. Special training provided to healthcare providers regarding the challenges of immigrant families may enhance awareness. Information and instrumental support may help to enhance parental coping and reduce isolation. Understanding the differences in perceptions between service providers and immigrant parents in regard to parental challenges will help government agencies, healthcare and social

service providers in the development of evidence-based policies, services and interventions to better support immigrant parents of children with disability. Future research should be conducted on larger populations with participants from a more diverse background and pay more attention to minority culturally and linguistically diverse groups particularly immigrant parents who are not English speakers. Such studies will add to the body of knowledge and increase awareness of the priorities and needs of non-English-speaking immigrant parents of children with disability.