

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

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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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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.**

Contents

Statement of Originality	ii
Acknowledgement of Authorship	iii
Acknowledgements	vi
Publications Arising from this Thesis	viii
Presentations Arising from this Thesis.....	viii
Awards.....	ix
List of Tables.....	xiv
List of Figures	xvi
List of Abbreviations.....	xvii
Chapter 1: Introduction	1
1.1 Background	1
1.2 Global Immigration	1
1.3 Immigration in Australia	2
1.4 Disability in Children and Immigration	4
1.5 Parental Challenges	5
1.6 Parental Coping and Resilience.....	7
1.7 National Disability Insurance Scheme	10
1.8 Problem Statement	13
1.9 Research Questions	13
1.10 Study Aim.....	14
1.11 Significance and Impact of the Study.....	14
1.12 Thesis Structure.....	15
Chapter 2: Literature Review	17
2.1 Abstract	17
2.2 Introduction	19
2.3 Methods	19
2.3.1 Literature Search.....	19
2.3.2 Inclusion and Exclusion Criteria	20
2.3.3 Data Evaluation	21
2.3.4 Data Analysis.....	21
2.4 Findings	31
2.4.1 Data presentation	31
2.4.2 Challenges of Raising Children with Disabilities.....	32
2.4.3 Coping Strategies Used by Immigrant Parents of Children with Disability.....	36
2.4.4 Resiliency factors associated with parental coping	38
2.5 Discussion	39
2.6 Limitations.....	43
2.7 Literature Gap.....	44
2.8 Summary	44
Chapter 3: Research Methodology and Methods.....	45
3.1 Introduction	45
3.2 Research Methodology.....	45
3.2.1 Quantitative approach.....	46
3.2.2 Qualitative approach.....	47

3.2.3 Mixed-methods approach	49
3.2.4 Types of mixed-methods design	50
3.3 Phase One: Quantitative Survey	54
3.3.1 Aim	54
3.3.2 Methods	54
3.3.3 Sampling	55
3.3.4 Inclusion criteria	55
3.3.5 Exclusion criteria	56
3.3.6 Sample size calculation	56
3.3.7 Instruments	56
3.3.8 Pilot testing	60
3.3.9 Data collection procedure	60
3.3.10 Statistical analysis	63
3.4 Phase Two: Qualitative Descriptive Study	64
3.4.1 Aim	64
3.4.2 Method	64
3.4.3 Interview technique	66
3.4.4 Sampling	68
3.4.5 Data collection procedure	69
3.4.6 Data analysis	71
3.4.7 Trustworthiness of qualitative study	72
3.4.8 Credibility	72
3.4.9 Transferability	73
3.4.10 Dependability	73
3.4.11 Confirmability	74
3.5 Ethical Consideration	74
3.6 Ethical Approvals	74
3.7 Informed Consent	74
3.8 Beneficence and Non-maleficence	75
3.9 Anonymity, Privacy and Confidentiality	76
3.10 Storage of Information	76
3.11 Summary	76
Chapter 4: Phase One Results	78
4.1 Introduction	78
4.2 Response Rate	78
4.3 Sample Characteristics	78
4.4 Challenges, Coping and Resilience of Immigrant Parents	82
4.4.1 Challenges	83
4.4.2 Coping	87
4.4.3 Resilience	90
4.5 Relationship between Challenges, Coping and Resilience	91
4.6 Challenges, Coping and Resilience among Groups of Different Sociodemographic Characteristics	94
4.7 Summary	106
Chapter 5: Phase Two Results	107
5.1 Introduction	107
5.2 Sociodemographic Characteristics of the Participants	107
5.3 Ongoing Challenges of Everyday Life	110

5.4 Ongoing Coping Tactics.....	118
5.5 Ongoing Help-Seeking Behaviours.....	120
5.6 Service Providers.....	122
5.7 Barriers.....	124
5.8 Facilitators.....	128
5.9 Summary.....	131
Chapter 6: Discussion	132
6.1 Aims and Research Questions.....	132
6.2 Response Rate.....	133
6.3 Participants Profile.....	133
6.4 Key Findings.....	136
6.5 Challenges of Immigrant Parents Raising Children with Disability.....	141
6.5.1 Overwhelming caretaking responsibilities.....	141
6.5.2 Lack of supportive social networks.....	142
6.5.3 Feeling embarrassed over children's behaviours.....	147
6.5.4 Adapting to a new culture.....	147
6.5.5 Similarities and differences in parental challenges of immigrant parents taking care of children with disability and other parents.....	149
6.6 Coping Strategies Used by Immigrant Parents of Children with Disability.....	150
6.6.1 Problem-focused coping.....	151
6.6.2 Emotion-focused coping.....	154
6.6.3 Positive gains from parental experience.....	156
6.7 Level of Resilience and Factors Affecting Resilience.....	157
6.8 Relationship among Challenges, Coping and Resilience.....	158
6.9 Perceived Barriers and Facilitators of Coping.....	160
6.9.1 Barriers.....	160
6.9.2 Facilitators.....	163
6.10 Summary of Findings.....	164
6.11 Study Strengths.....	166
6.12 Study Limitations.....	168
6.13 Implications for Practice and Policy Development.....	169
6.14 Implications for Global Communities.....	175
6.15 Directions for Future Research.....	176
6.16 Conclusion.....	177
References	179
Appendices	205
Appendix A: Published Literature Review.....	205
Appendix B: Copyright Clearance.....	215
Appendix C: Permissions.....	215
Appendix D: Zarit Burden Interview.....	218
Appendix E: The Family Crisis Oriented Personal Evaluation Scales (F-COPES).....	219
Appendix F: Connor-Davidson Resilience Scale (CD-RISC 10).....	220
Appendix G: Sociodemographic Sheet, Parents.....	221
Appendix H: Information Sheet, Organisations.....	223
Appendix I: Consent Form, Organisations.....	227
Appendix J: Poster, Parents.....	228
Appendix K: Information Sheet, Parents.....	229

Appendix L: Consent Form, Parents	233
Appendix M: Poster, Service Providers	235
Appendix N: Information Sheet, Service Providers	236
Appendix O: Sociodemographic Sheet, Service Providers	240
Appendix P: Consent Form, Service Providers	241
Appendix Q: Sample Transcript.....	242
Appendix R: Ethics Approval	250

List of Tables

Table 1 Critical search terms and the expanded terms.....	20
Table 2 Summary of the extracted data from reviewed studies	23
Table 3 Generated Themes and sub-themes.....	31
Table 4 Response Rate of Immigrant Parents in Each Region (n = 134)	78
Table 5 Sociodemographic Characteristics (n = 134).....	80
Table 6 Characteristics of Immigrants' Children with Disability (n = 134).....	82
Table 7 Differences between Newcastle and Sydney Participants in Challenges, Coping and Resilience	83
Table 8 Levels of Challenges on the ZBI	84
Table 9 Summary Scores of ZBI (n = 134).....	84
Table 10 Consequences of Caregiving Subscale (n = 134)	85
Table 11 Exhaustion and Uncertainty Subscale (n = 134).....	86
Table 12 Child's Dependence Subscale (n = 134).....	86
Table 13 Guilt and Fear of Child's Future Subscale (n = 134).....	87
Table 14 Summary Scores of F-COPES (n = 134)	87
Table 15 Reframing Coping Subscale (n = 134).....	88
Table 16 Accepting Help from Others Subscale (n = 134).....	89
Table 17 Seeking Spiritual Support Subscale (n = 134)	89
Table 18 Acquiring Social Support Subscale (n = 134).....	90
Table 19 Passive Appraisal Subscale (n = 134).....	90
Table 20 CD-RISC 10 Mean Scores	91
Table 21 Correlation between Study Variables (n = 134)	93
Table 22 Differences between Mothers and Fathers in Challenges, Coping and Resilience Scores	94
Table 23 Differences in Challenges, Coping and Resilience Scores between Immigrant Parents based on Child's Gender	95
Table 24 Differences between Immigrant Parents Who Had Close Family Living in Australia and Those Who Did Not in Challenges, Coping and Resilience.....	96
Table 25 Challenges by Different Religion Group	98
Table 26 Challenges, Coping and Resilience by Educational Level	99
Table 27 Challenges Subscales by Education Level.....	100
Table 28 Coping Subscales by Education Levels	101
Table 29 Challenges, Coping and Resilience by Different Relationship Status	102

Table 30 Differences among Groups based on Monthly Household Income	103
Table 31 Differences in Coping Subscale among Different Monthly Household Income Groups	104
Table 32 Difference in Challenges, Coping and Resilience among Different Numbers of Children	104
Table 33 Differences in Challenges, Coping and Resilience in Groups with Different Immigration Periods.....	105
Table 34 Challenges Subscales by Immigration Period.....	106
Table 35 Characteristics of the Immigrant Parents (n = 9)	108
Table 36 Immigrant Parents' Characteristics	109
Table 37 Themes and Subthemes that Emerged from Interviews with Immigrant Parents	110
Table 38 Characteristics of the Service Providers (n = 9)	123
Table 39 Themes and Subthemes that Emerged from Service Providers	124
Table 40 Relationship of key findings with the five research questions and alignment with Phases 1 and 2 of the study	140

List of Figures

Figure 1. Search procedure and outcome	21
Figure 2. Sequential explanatory mixed-methods design in this study.....	53
Figure 3. Conceptual framework of the study's findings.....	165

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.

Chapter 1: Introduction

1.1 Background

Parenting children with disabilities poses challenges and creates stress for the parents. Immigrant parents face additional challenges such as adjusting to a new environment and culture. It is important to understand the challenges, coping and resilience of immigrant parents of children with disability and their experience in the caregiving role. Such understanding will facilitate government agencies, and healthcare and social service providers in the development of evidence-based policies, services and interventions to better support immigrant parents. The primary aim of this mixed methods study is to examine the challenges, coping and resilience of immigrant parents in Australia raising children with disability.

Chapter 1 provides an overview of global immigration and focuses on immigration in Australia. It also provides an overview of the challenges, coping and resilience of immigrant parents raising children with disabilities. The main aim, the objectives and the research questions of the current study are presented. The problem statement and the significance of the study are also discussed.

1.2 Global Immigration

Immigrant flow continues to increase globally. There were approximately 272 million international migrants around the world in mid-2019. About 23 million of these immigrants migrated as refugees for humanitarian reasons (United Nations High Commissioner for Refugees [UNHCR], 2019). An estimated 12% of the international migrant stock were children under 18 years of age (United Nations Department of Economic and Social Affairs [UN DESA], 2019).

In some countries, the number of immigrants is increasing, and they make up a major part of a country's population. In the United Arab Emirates, international

immigrants make up 88% of the total population (UN DESA, 2019). In the United States (US), the number of immigrants is expected to reach 45 million by the end of 2020, which is about 15% of the total population (Zong, Batalova & Burrows, 2019).

1.3 Immigration in Australia

Australia is a country of rich cultural diversity. As of 2019, it has a total population of 25.5 million with more than 300 languages spoken, over 100 religions and more than 300 different ancestries (Australian Bureau of Statistics [ABS], 2019).

Australia has experienced about 25 % growth in total population in the last 10 years due to immigration (ABS, 2019). Within Australia, New South Wales (NSW) has the largest immigrant population-over 8 million.

From 2018–2019, the net overseas migration to Australia reflected an annual gain of 238,300 people, which is 1.6% higher than expected due to refugee immigration (ABS, 2019). There are many reasons for immigration, such as study or work or for humanitarian reasons, as for refugees and asylum seekers (Australian Government, 2017). Immigrants migrating to Australia are categorised into different settlement streams by the Australian Government. The main migrant streams in Australia are skilled occupation migrants, student migrants, family reunion migrants, investor migrants and migrants for humanitarian reasons (ABS, 2019). The skilled occupation stream occupied the first rank of migration streams, which accounted for 69.8% of immigrants. The countries providing the largest sources of skilled migrants were India, China, the United Kingdom (UK), the Philippines and New Zealand (Australian Government, 2019).

In 2018–2019, Australia received 18,750 immigrants via refugee and humanitarian programs. Australia's humanitarian programs focus on three priority regions—the Middle East, Asia and Africa. The main groups that migrated to Australia for humanitarian reasons were Syrians, Iraqis, Myanmar, Afghans, Bhutanese

(Australian Government, 2019). In 2016, the United Nations International Children's Emergency Fund (UNICEF) estimated that 11 million children were living as refugees outside their country of birth (UNICEF, as cited in Australian Government, 2019), and the number continues to increase due to an increase in migration influx.

Australia is one of the few countries that specifically supports the resettlement of women at risk of victimisation, harassment or serious abuse based on their gender. More than 20,500 Woman at Risk visas have been granted since 1989 via the Woman at Risk program. In 2019, Australia granted the highest number of risk visas to women and their dependents, usually their children (2,126 people in total) (Australian Government, 2019).

The cultural and linguistic diversity of Australia's population has been reshaped over many years by immigration. Immigration can help to build a country's economy, shape society, support the labour market and reunite families (Larsen, 2013). This diversity creates important economic and cultural benefits for the Australian population. Studies have found a positive relationship between diversity in staff, particularly immigrant workers, and the performance of multinational corporations (Larsen, 2013). Culturally diverse staff members bring new ideas, skills and technology, racial and cultural understanding, and contacts. They can help to reduce skill shortages, develop new businesses, contribute to technological development and enhance knowledge of international business markets (Tiong et al., 2006).

However, immigration may also pose special challenges to the host country, such as providing healthcare, education, and social and employment support to immigrants. Immigrants may have pre-existing health issues, which could increase the healthcare burden of the host country; such health issues include psychological disorders, poor dental health, infectious diseases, anaemia, nutritional deficiencies,

incomplete immunisations, and delayed growth and development in children (Tiong et al., 2006).

Due to immigrants' lack of familiarity with the Australian healthcare system, newly arrived immigrant families require comprehensive and culturally appropriate guidance to access healthcare services. However, many find it difficult to access such services. Language and cultural issues, health beliefs and unfamiliarity with health systems are well-documented barriers to accessing needed healthcare (Neale, Ngeow, Skull & Biggs, 2007). For example, a study found general practitioners (GPs) reported difficulties in providing service to immigrants due to difficulties with interpreters and immigrants' lack of familiarity with the Australian healthcare system (Neale et al., 2007). Some GPs were therefore reluctant to treat immigrants, especially those with complex health issues. Parents who had children with a disability also reported difficulties in accessing the needed healthcare for their children (Neale et al., 2007).

1.4 Disability in Children and Immigration

'Disabilities' is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure (World Health Organization [WHO], 2001, p. 10). An activity limitation is a difficulty encountered by an individual in performing a task or action. Participation restriction is a problem experienced by an individual in involvement in life events or situations. Thus, disability is not just a health problem. It is a complex phenomenon, reflecting the interaction between features of the persons' body and features of the society in which they live. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. (World Health Organization [WHO], 2001).

In this study, 'disability' refers to any level of permanent physical or mental problem that makes it difficult for a child (0–18 years old) to walk, see, hear, learn or

communicate (Phillips, 2012). Examples of health conditions in children with disabilities are cerebral palsy, traumatic spinal cord injury, autism and Down syndrome; disability includes hearing, visual, physical, communication, behavioural and intellectual impairment (World Health Organization [WHO], 2012). Parenting children with disabilities creates challenges and stress for not only the parents but the whole family (Jegatheesan, Fowler & Miller, 2010).

There has been an increase in the prevalence of childhood disability around the world. For example, recent estimates in the US showed that about one in six, or about 17%, of children aged 3–17 years have one or more health conditions that caused developmental disabilities such as autism, cerebral palsy and intellectual disabilities. During 2014–2016, the prevalence of children aged 3–17 years who had ever been diagnosed with a developmental disability increased from 5.76% to 6.99% (National Health Interview Survey, 2014). In the UK, 7.3% of children were reported as children with disability—the majority being immigrant children (Joseph Rowntree Foundation [JRF], as cited In Zhou, 2015). An Australian study found that people from culturally and linguistically diverse (CALD) backgrounds had a similar level of disability as Australian-born people (18.5%). However, there was a greater rate of profound and severe disability and a higher level of need for assistance in undertaking core activities in CALD people (Zhou, 2015).

There is a lack of global statistics on disability among immigrants, particularly statistics on children with disabilities in immigrant families. In Australia, statistics on the number of immigrant parents raising children with disabilities are difficult to obtain, reflecting a general lack of awareness about the issues faced by this group (Refugee Council of Australia [RCOA], 2019). The lack of statistics is a major barrier to effective service planning and delivery. Immigrant parents of children with disabilities found

enormous gaps in service delivery and a lack of specialised support for them and their children (RCOA, 2019).

1.5 Parental Challenges

Many terms have been used to describe the challenges that the parents encountered when raising children with disabilities, Terms like challenges, burdens, needs, and concerns were used interchangeably . In this study, the term ‘challenges’ is used to describe burdens and needs of immigrant parents raising children with disabilities in Australia. Parenting children with disabilities poses special challenges. These parents face additional stress when compared to parents of children without disabilities. Being new immigrants in a host country can further complicate parents’ experiences (Su, 2008). Immigrant parents attempt to rebuild their lives in a new home in a new country. They face challenges within their households, such as family role reconstruction and family relationship change. They are also surrounded by challenges from outside the home, such as learning a new language and new social rules, applying for citizenship, finding a job, and coping and adjusting to a new environment and culture (Su, 2008).

Immigrant families raising children with disability may find it challenging to navigate new healthcare, education and social services in the host country (RCOA, 2019). Language barriers, low family income (Fellin, 2013; Luther, Canham & Young Cureton, 2005), inflexible service offerings by the host country and reduced social networks are often reported as overwhelming challenges (Greenwood, Habibi, Smith & Manthorpe, 2014). The literature has also highlighted stigma and isolation from extended family and community as challenges for immigrant parents raising children with disability (Bradby et al., 2007).

If the immigrant parents’ needs are not adequately met, they may not be able to cope with the challenges of caring for their children with disabilities. Parents may

experience severe stress, which may affect their physical and mental health.

Consequently, this may adversely affect the care that parents are able to provide to their children with disabilities and their siblings. Long-term emotional and social problems may occur that may break down the family unit (Bradby et al., 2007).

If children with disabilities receive inadequate and non-equitable healthcare, education and social services, this may lead to poor health, complicate learning and inhibit functioning and development. The children may not be able to develop independent living skills. This then places a much greater burden on the parents. Long-term financial costs due to the burden of care will be increased for the parents, the family, the community and the government (Multicultural Disability Advocacy Association, 2002).

The majority of current available evidence related to immigrant families raising children with disability stems mainly from studies conducted in the US and Canada. Little is known about immigrant parents' challenges and experience of taking care of their children with disabilities in Australia. Such understanding is important for policymakers and providers of disability services so that they can provide appropriate and effective services to these parents and their children.

1.6 Parental Coping and Resilience

Coping involves purposeful attempts to manage stress regardless of effectiveness (Compas, Malcarne & Fondacaro, 1988). Adaptive coping refers to cognitive and behavioural efforts to manage internal and external demands that are taxing or exceeding the resources of the person (Lazarus & Folkman as cited in Docena, 2015, p. 29).

Immigrant parents use a variety of coping strategies to manage the challenges of taking care of their children with disabilities. Previous studies showed that some immigrants found religious support, having hope and a positive outlook on life to be

helpful in coping with their situation (Martinez, 2005). Al-Azzam (2011) highlighted that having a support system of family and friends, which they could spend time with and rely on, is a vital factor in helping immigrant families to cope and manage challenges. Additional support from healthcare staff has also been reported to be very encouraging in its effect on the caregiver's experience of managing challenges (Leow & Chan, 2017). However, while some immigrant parents tried to manage their challenges by finding solutions to their problems, others preferred to ignore the issue, resulting in denial of the problems (Luong, Yoder & Canham, 2009). Some immigrant parents coped by avoiding situations they found difficult, such as social activities and community gatherings. Consequently, they became more isolated (Croot, Grant, Mathers & Cooper, 2012).

Very few studies have been conducted in Australia on the coping experience of immigrant parents with a child with a disability. There is little understanding about how these parents have coped, the coping strategies used and whether they regarded these coping strategies as useful. Such understanding is important for service providers, so they can assist immigrant parents raising children with disabilities in their coping processes and thereby facilitate their coping.

Caring for a child with disability has traditionally been perceived as an extremely stressful process. This view can be criticised as focusing only on the negative aspects of caring. The dominance of the stress-burden model in healthcare and on social and family services might mean that interventions have focused mainly on burden reduction with little attention given to the positive side of caregiving (Chan, 2010; Chan, 2011). Thus far, few studies have been conducted to understand the positive aspects of caring among immigrant parents raising children with disabilities. It is important for service providers to understand these positive aspects, so they can foster

the positive perspectives and empower the immigrant parents in their experience of raising children with disabilities.

Folkman's (1997) revised the stress and coping model. The new model explains that both positive psychological appraisals and burdens can be experienced concurrently by family caregivers. Thus, caring for a child with a disability can be viewed as a mutual meeting of needs between the parents and the child. This model provides an explanation as to why some parents adapt to their caregiving roles better than others. Protective factors, such as resilience, could mediate or moderate parental burden (Folkman, 1997). However, little is known about the facilitators and barriers affecting immigrant parents' coping in raising their children with disabilities. It is important for service providers to be aware of and understand the facilitators and barriers so that they can develop interventions to promote the facilitators and help parents overcome the barriers.

'Resilience' is defined as the process of adapting well in the face of adversity or various sources of stress such as family and relationship problems, serious health problems or financial stressors (American Psychological Association [APA], 2014). Resilience involves protective, attenuating and recovery factors and incorporates resources across personal, relational and environmental domains (Windle, 2011). Some of these resources are internal (such as adaptive coping behaviours) and others are external (such as useful government policies or access to a responsive and attuned social support network) (Windle, 2011). Resilience can be referred to as the ability to adjust rapidly and in a healthy manner to adversity (Windle, 2011).

Resilient individuals may experience the same stressful experiences as non-resilient people. However, they have protective mechanisms in place to deal with these difficulties and are able to return to a state of equilibrium and balance quickly (Windle, 2011). When these protective factors are present for an individual at the time of

experiencing the adverse event, they help buffer the effects of the perceived negative experience and provide a more positive outcome. Research has shown that resilience protects against, and can sometimes reverse, depressive episodes, anxiety, fear, helplessness and similar negative emotions (Wagnild, 2009).

There have been studies on caregiver resilience in dementia care, mental health care and cancer care (Chan, 2011; Chan, 2010; Leow & Chan, 2017), and in parents raising children with disabilities (Breitkreuz, Wunderli, Savage & McConnell, 2014; McConnell, Savage & Breitkreuz, 2014), but not on immigrant parents caring for a child with a disability. To the best of our knowledge, no study has been conducted on the association between resilience, parental challenges and coping. It is important to examine parental resilience in caring for a child with a disability as knowledge of how resilience is associated with parental challenges and coping will help to develop interventions to promote resilience in these parents.

1.7 National Disability Insurance Scheme

The National Disability Insurance Agency (NDIA) is an independent statutory agency in Australia. Its role is to implement the National Disability Insurance Scheme (NDIS), a national insurance scheme designed to empower people with disability to work towards achievements; identify the disability related support they need; and access personal care, transport and community activities (Council of Australian Governments [COAG], 2017). NDIS is considered the largest social policy reform in Australia since the introduction of Medicare (Productivity Commission, 2017).

The NDIS was established in 2013 following recommendations from the 2011 Productivity Commission report, which described Australia's disability support arrangements as inequitable, underfunded, fragmented and inefficient (COAG, 2017). It is a fundamental shift in disability funding and services policy. NDIS has been described as one of the most important social reforms in recent history in relation to the

welfare of people with a disability, with real potential to improve the lives of individuals with a disability in Australia (RCOA, 2019).

The NDIS covers eligible individuals of the Australian population, people of Aboriginal and Torres Strait Islander backgrounds, and immigrants with permanent Australian residency. In July 2016, NDIS moved from a trial phase to a full national rollout. About 6,814 employees, including early childhood supporters, therapeutic supporters, case managers and transport assistance workers, are employed under the umbrella of NDIS. Almost half work in NSW (COAG, 2017).

In addition to its regular services, NDIS helps immigrant individuals with disabilities and their families to practice their cultural or religious beliefs or traditions, participate in cultural community groups, strengthen their social connections and identify and employ support workers based on individual cultural needs. While the focus of the NDIS plan is the child with disability, the types of support in the child's plan may also have direct or indirect benefits for families and carers, such as training sessions and face-to-face support groups for family members and carers (COAG, 2017).

More than 78,000 Australians with a disability benefit from the NDIS, of which 38,163 individuals are from NSW. About 2,000 of the individuals supported by the NDIS are immigrants from different countries such as China, Iraq, Syria and the Democratic Republic of the Congo. It is expected that demand for NDIS support will grow dramatically in the near future and will cover 460,000 people with disabilities by the end of 2020, including individuals from different cultural backgrounds. The funding for NDIS will reach A\$22 billion per year (RCOA, 2019). In NSW, 51% of individuals covered by NDIS are children of 0–18 years old. Of these children, 37% suffer from intellectual disabilities and 26% from autism (COAG, 2017). There are no statistics yet available on immigrant individuals, particularly immigrant children with disabilities, who benefit from the NDIS.

Eligibility criteria for accessing the NDIS include being an Australian citizen or holder of a Permanent visa or a Protected Special Category visa, being aged under 65 years, having evidence of a permanent impairment or condition that significantly impacts functional capacity, or psychosocial functioning in the activities of daily life and social and economic participation, or having early intervention requirements (RCOA, 2019). Under NDIS rules, only Australian citizens and permanent residents can access the scheme, while people seeking asylum (such as those on bridging visas), refugees on Temporary Protection visas and those on student visas are not able to access the NDIS.

The Australian National Ethnic Disability Alliance reported that about 1.5 million people (21.9%) from the CALD community have disabilities. However, the NDIS report showed that 600,000 people from CALD backgrounds accessed the scheme—representing only about 9.0% of all participants. There is certainly an accessibility gap (RCOA, 2019). The NDIS assumes that individuals from minority groups and those for whom English is not their first language are informed about the support that is available to them, but evidence suggests that only a minority is able to take advantage of the services they are entitled to (RCOA, 2019). The structure of NDIS services assumes that those people accessing the scheme understand their own needs, understand Australia's complex system of services and are proficient in English. However, this is obviously not the case for immigrants who are not English speakers and/or migrated from countries with a different healthcare system (RCOA, 2019).

It is well known that parents raising children with disabilities face challenges that hinder the development of a social network and social life (Jegatheesan et al., 2010). Immigrant parents face cumulative disadvantage as a result of experiencing further marginalisation through the exclusion and discrimination that is related to using disability services (RCOA, 2019). The existing barriers to accessing this service need to

be acknowledged and considered by the Australian Government to make adjustments towards a more inclusive NDIS. A greater understanding of the challenges faced by immigrant parents raising children with disabilities in accessing disability services will help to develop strategies to ensure a higher participation rate and better outcomes.

1.8 Problem Statement

The prevalence of childhood disability combined with an increased influx and diversity of immigrant families in Australia indicates a need to improve childhood disability services for immigrant families. Studies have explored the double impact of immigration and disability on families (Flores, 2012; Jegatheesan et al., 2010; Yu, 2013), but few have addressed the interrelation of immigration and disability affecting the lives of families. Some Australian studies have explored the impact of disability on families, but not on immigrant families. It is important to have an in-depth understanding of the experiences, challenges and needs of immigrant parents in taking care of a child with disability in Australia. It is also important to examine the coping strategies and resilience of immigrant parents and determine how resilience influences parental perceived challenges and coping. Such understanding is the first step in developing appropriate and equitable services for parents and their children with disability. This study will fill the present knowledge gaps in the challenges, coping and resilience of immigrant parents taking care of children with disability in Australia. To the best of this researcher's knowledge, this is the first study on this specific topic.

1.9 Research Questions

This study is guided by the following research questions:

1. What do immigrant parents raising children with disability in Australia perceive as everyday challenges?
2. What are the coping strategies used by immigrant parents to overcome these challenges?

3. What is their level of resilience?
4. What are the relationships among challenges, coping strategies and resilience?
5. What are the perceived barriers and facilitators of coping among parents with children with disability?

1.10 Study Aim

The main aim of this study is to examine the challenges, coping strategies and resilience of immigrant parents raising children (0–18 years old) with disability.

The objectives are to:

- explore parental challenges;
- examine parental coping strategies;
- examine parental level of resilience;
- investigate the relationships among challenges, coping strategies and resilience; and
- explore the barriers and facilitators of coping.

1.11 Significance and Impact of the Study

The study will add new knowledge on the challenges, coping and resilience of immigrant parents raising children with disability. The findings will extend the understanding of the impact of immigration on parents raising children with disability. This study will enhance our understanding of how resilience influences perceived challenges and coping. The study will also identify factors that either facilitate or act as barriers to parental coping. The findings of the study will help to build a comprehensive model that explains the relationship among perceived challenges, coping and resilience of immigrant parents in taking care of children with disability.

The knowledge generated from this study will help policymakers review existing policies or develop new policies to provide viable, equitable and culturally sensitive services for immigrant parents raising children with disability. The new

evidence will help service providers understand immigrant families' needs, challenges, coping and resilience. Such understanding is important to build trust between immigrant parents and service providers. This study will encourage service providers to develop culturally and linguistically appropriate plans and services to immigrant parents.

The new knowledge generated from this study can also be used to develop evidence-based service guidelines and recommendations to improve service provision to immigrant parents. Further, it will help service providers to direct immigrant parents to access appropriate resources provided by the government, and other public and private institutions.

The findings of this study will be published in international refereed journals and presented at local and international conferences. A report of this study will be submitted to NDIS. The study was conducted in Australia, but the findings will have global relevance for countries with similar immigration policies to Australia. Through the dissemination of findings, the study will provide policymakers and healthcare, social services and education providers with high-level evidence to enhance their understanding of challenges, coping and resilience in immigrant parents of children with disability. This will help them to make evidence-based decisions to ensure appropriate policies are established and appropriate services are provided to immigrant parents of children with disability. The study will also contribute to the debates on the human rights of immigrant parents and their children with disability.

1.12 Thesis Structure

This thesis comprises six chapters. Chapter 1 has provided an overview of the background of the study. Chapter 2 reviews the literature and summarises the evidence on this topic to identify gaps in the literature that inform the direction of the present study. Chapter 3 discusses the study's methodology. Chapter 4 presents the quantitative findings of the first phase of the study. Chapter 5 presents the themes and sub-themes

that emerged from the qualitative data of the second phase of the study. Chapter 6 integrates and discusses the quantitative and qualitative findings.

Chapter 2: Literature Review

Chapter 2 consists of an integrative literature review which aimed to synthesize evidence on challenges in caring for children with disabilities among immigrant families, coping strategies used by immigrant parents to manage their children's disabilities, and resiliency factors associated with their coping.

This chapter was disseminated in the following publication (see Appendix A):

Alsharaydeh, E., Alqudah, M., Lee, R., & Chan, S. (2019). Burdens, Challenges, Coping and Resilience in Caring for a Child with A Disability among Immigrant Parents: An integrative review. *Journal of Nursing scholarship*, 51(6), 670-679. <https://doi.org/10.1111/jnu.12522>. Permission to use the published literature review in the current thesis has been obtained from the publisher (see appendix B). The publication has been updated to include one more new study that was published in the year 2019 (Sritharana & Koola, 2019).

2.1 Abstract

Purpose: The aim of this integrative review is to synthesize quantitative and qualitative research evidence on challenges in caring for a child with a disability among immigrant parents and to understand their coping strategies and resiliency factors associated with their coping.

Methods: A comprehensive literature search was conducted to identify relevant studies from the following databases: MEDLINE, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, PsycINFO, Social work abstract, Cochrane library, and EMBASE.

Findings: This review included 26 studies: 1 quantitative, 23 qualitative, and 2 narrative reviews. The main challenges that parents faced were language barriers, financial hardships, service utilization challenges, poor adaptation to new culture,

stigma related to mental illness, discrimination, and social isolation. This review found poor communication and lack of cultural awareness among some healthcare professionals. Immigrant parents used problem-focused coping, avoidance coping, spiritual coping, and social support to manage their challenges. Parents who received social, emotional, and instrumental support were more resilient. Personality traits and faith were protective factors that enhanced resilience.

Conclusions: When immigration and disability are considered concurrently, the burden of care multiplies. Immigrant parents with children who have disabilities faced extra challenges related to adaptation, finance, service utilization, and stigma. Healthcare providers can play an important role in aiding these parents in service utilization and adaptation.

Significance: This review adds new knowledge on immigrant parents' challenges in caring for their children with disabilities. Such knowledge could help health professionals to develop supportive interventions to enhance parental coping and resilience.

Clinical relevance: Culturally appropriate and sensitive communication and care provided by healthcare providers can facilitate service utilization and reduce perceived stigma. Special training provided to healthcare providers regarding the challenges of these families may enhance awareness. Information support and parental support groups may help to enhance parental coping and reduce isolation. An interpreting service should be provided in all aspects of care.

2.2 Introduction

With the increasing global immigration, children with disabilities immigrated with parents. We do not have an adequate understanding of the perceived challenges of immigrant parents on taking care of their children with disabilities as well as their resilience and coping strategies. An integration of both quantitative and qualitative empirical evidences contributed to a deeper understanding of the relationship among immigration and taking care of children with disability, parents' perceived challenges, their resilience and coping. Based on the integrative literature review, knowledge gaps were identified, which guided the directions of the current study.

2.3 Methods

This integrative literature review was conducted using a five-stage approach: problem identification, literature search, data evaluation, data analysis and presentation (Whittemore & Knafl, 2005). This approach has been used extensively to enhance the rigor of the review process in many published integrative reviews (Hopia, Latvala, & Liimatainen, 2016).

2.3.1 Literature Search

An extensive search of the literature was conducted which included both qualitative and quantitative primary and secondary studies. The databases searched included MEDLINE, CINAHL, Scopus, PsycINFO, Social work abstract, Cochrane library, EMBASE using the identified key words “immigrant”, “developmental disability*”, “coping”, “resilience”, “stigma*” and “need*”. The search included articles published in English between the year 2000 to 2019. Table 1 presents the critical search terms and expanded terms. The search used all the keywords and index terms across all databases. During search process, consideration was given to the diverse terminology used, synonyms, and the spelling of keywords. We also conducted a manual search. In the keyword search, the term challenges, burdens, needs, and

concerns were used. As all these words are used interchangeably in the literature, we use the term ‘challenges’ to report the findings in this integrative review.

Table 1

Critical search terms and the expanded terms

The searched term	The expanded terms
“immigrant”	“migrant”, “refugee”, “asylum seeker” and “overseas-born”
“developmental disability*”	“neurocognitive disorders”, “neurodevelopmental disorders”, “attention deficit disorder”, “autism spectrum disorder”, “intellectual disability”, “learning disorders”, “schizophrenia, childhood” and “cerebral palsy”
“coping” “need*”	“cope” and “copes” “challenge*”, “burden*”, “concern*” and “life experience*”
“famil*” “resilience”	“parent*”, mother*, father* “resilie*”

2.3.2 Inclusion and Exclusion Criteria

This review included studies that focused on immigrant parents-mothers or/and fathers who had one or more children (< 18 years old) with disabilities and had migrated to host country regardless of their immigration period. Studies that explore service providers’ perspective in immigrant parents’ experience in caring for children with disabilities are included. This review excluded studies focused experiences of immigrant parents of an adult with a disability. Literature that only focused on immigrant parents’ challenges during child’s diagnosis were excluded. We also exclude literature published in languages other than English.

The initial search identified 1,208 titles. Another seven articles from references and citations that were seemingly relevant were retrieved and assessed. We excluded duplicated entries, leaving 744 titles. The title, abstract and whole text were assessed based on the inclusion and exclusion criteria. A total of 716 articles were removed with 28 articles remained.

2.3.3 Data Evaluation

The 28 articles were appraised for quality using the Joanna Briggs Institute (JBI) Assessment and Review Instruments (Joanna Briggs Institute, 2014). After the appraisal, two qualitative studies were excluded because of incongruity between the research methodology data collection method, data analysis and interpretation of results (Decoteau, 2017; Ravindran & Myers, 2013). Finally, 26 studies were included in this review: 23 qualitative studies, one quantitative study, and two narrative review. Figure 1 presents the search procedure and outcome.

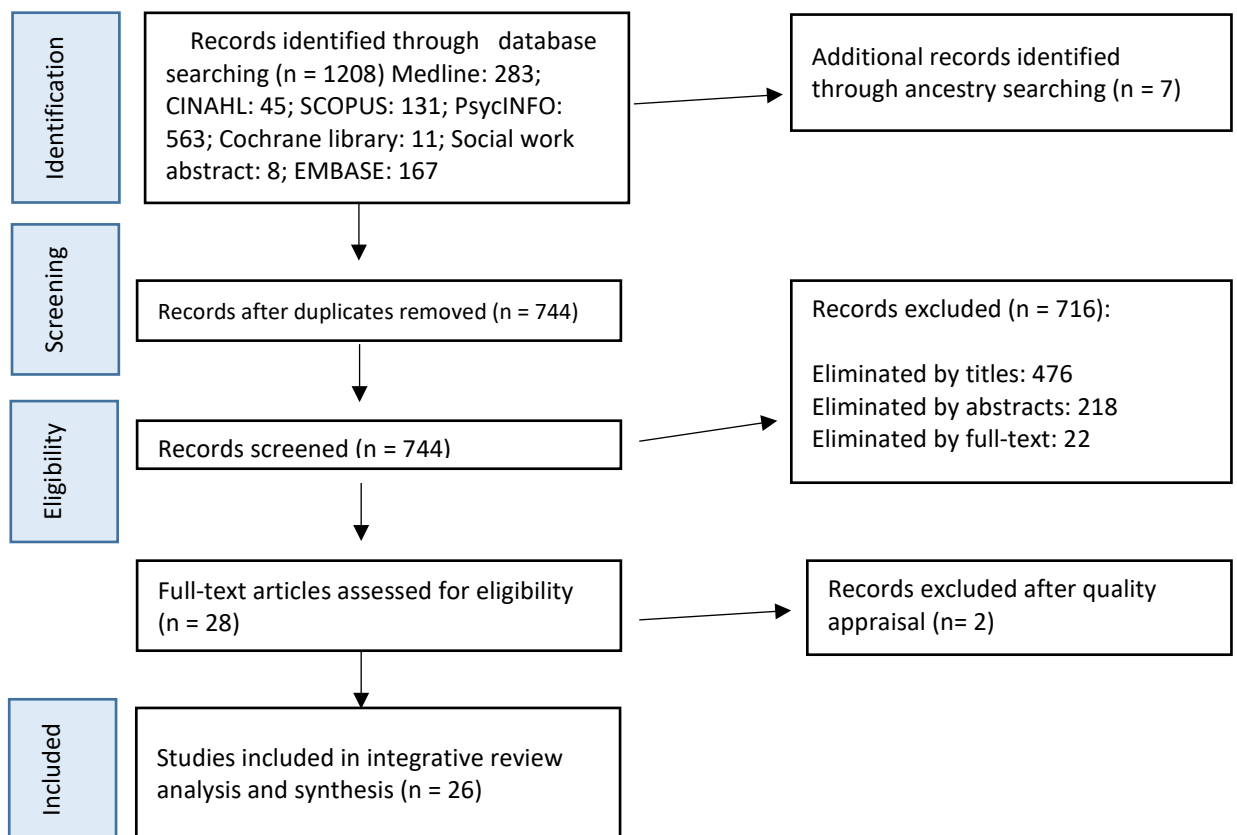


Figure 1. Search procedure and outcome

2.3.4 Data Analysis

Once each study had been fully assessed for inclusion, another independent reviewer confirmed the included studies. Data were extracted from each study. The researcher identified themes related to parental challenges, parental coping, and resiliency factors. Data were extracted independently by the researcher into a summary

table to capture the following information: author, year published, country of origin, study design, method, sampling approach and the key findings for each study. Next, the researcher met with the supervisory team to corroborate findings and agree on the final list of extracted data. As in prior steps, if a discrepancy was noted, it was discussed among the researcher and the supervisory team to obtain consensus. Once complete, a summary table of the findings was generated (see Table 2).

Table 2

Summary of the extracted data from reviewed studies

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
1.	Al-Azzam (2011) US	Qualitative descriptive design	Semi-structured interview	Purposeful sampling 16 mothers	Arab immigrant mothers	Attention Deficit Hyperactivity Disorder	<ul style="list-style-type: none"> Family members, friends and children's school as support systems for the parents. Stigma of using health facilities
2.	Alvarado (2004) US	Qualitative design	In-depth interviews, archival data, and participant observation	Purposeful sampling 2Mothers	Mexican mothers	Microcephaly	<ul style="list-style-type: none"> Financial challenges.
3.	Beatson (2013) US	Grounded theory qualitative design	Semi-structured and open-ended interview	Purposeful sampling 5 mothers 1 father	Somali Bantu mothers	Intellectual, Mental and physical disabilities.	<ul style="list-style-type: none"> A misunderstanding between health professionals and parents. Immigrant parents reported that they did not receive the level of care and sensitivity which would have been expected within their culture from health professionals.

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
4.	Blanche (2015) US	Descriptive qualitative design	In-depth semi-structured Interviews	Purposeful sampling 12 mothers 3 fathers	Latino parents	Autism Spectrum Disorder	<ul style="list-style-type: none"> • Parents used passive coping to deal with stigma and isolation from family and community. • Language barriers and lack of awareness of host country system were challenges.
5.	Bradby (2007) UK	Qualitative design	Semi-structured interview and focus group	Purposeful sampling 6 mothers 2 fathers	Asian parents	Mental disability	<ul style="list-style-type: none"> • Stigma surrounding mental illness. • Discrimination from health, education and social care professionals. • Immigrant parents were actively trying to disengage from the services because they felt that the service were culturally inappropriate services.
6.	Croot (2012) UK	Qualitative exploratory approach	In-depth interview	Purposeful sampling 7 mothers 3 fathers	Pakistani parents	Learning disability with or without additional physical or sensory disabilities.	<ul style="list-style-type: none"> • Religious beliefs, sharing care with others, using community support, recognising and enjoying the rewards of caregiving helped parents for coping.

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
7.	Fox (2017) UK	Community-based participatory research approach	In-depth interview	Purposeful sampling 12 mothers 3 fathers	Somali parents	Autism Spectrum Disorders	<ul style="list-style-type: none"> • Parents reported stigma • Religious beliefs helped parents to overcome their challenges and cope well.
8.	Gregoire (2011) US	Phenomenology approach	Open-ended interview	Purposeful sampling 8 mothers 2 fathers	Haitian parents	Learning Disabilities; Emotional Behavioral Disabilities; Intellectual Disabilities; and Traumatic Brain Injuries	<ul style="list-style-type: none"> • Parents tended to be educated more than before, used community resources to find solutions and cope with their child's disability.
9.	Heer (2015) UK	Qualitative design	In-depth interview	Purposeful sampling 5 mothers 2 fathers	South Asian parents	Developmental disability	<ul style="list-style-type: none"> • Adapting to a new culture is challenging • Immigrant parents who were speaking English fluently were more resilient.
10.	Ijalba (2016) US	Phenomenological qualitative approach	In-depth three stages interview	Purposeful sampling 22 mothers	Hispanic parents	Autism Spectrum Disorders	<ul style="list-style-type: none"> • Parents reported stigmatization and social isolation.

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
11.	Jegatheesan (2010) US	Ethnographic design	In-depth interview with parents observation.	Purposeful sampling 3 mothers 3 fathers	South Asian parents	Autism Spectrum Disorders	<ul style="list-style-type: none"> • A misunderstanding between health and education professionals and parents. • Immigrant parents avoided utilising healthcare services because they perceived health professionals as being cold and showing little or no interest in their cultural background
12.	John (2016) US	Descriptive quantitative design	Online survey Support Questionnaire and Sources of Social Support Scale	Purposeful sampling 25 mothers 8 fathers	Indian parents	Developmental disabilities	<ul style="list-style-type: none"> • Spouse and support groups were rated as sources of support. • Participants' stress levels were inversely linked to formal support.
13.	Khanlou (2015)	Applying Green, Johnson & Adams' methodology	Narrative review	59 studies	Different cultural background	Different type of disabilities	<ul style="list-style-type: none"> • Parents experienced financial and social challenges, including avoidance community gathering, stigma and isolation.

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
14.	Khanlou et al., (2015) Canada	Qualitative descriptive design	Open-ended interview	27 service providers	Canadian health care providers	Different type of disabilities	<ul style="list-style-type: none"> • Service providers emphasized that excessive paper work that immigrant parents required to complete in English is a main challenge. • Service providers noted that immigrant mothers do not realize that access to health and education are their basic rights. • parents who received social, instrumental, and emotional support being more resilient.
15.	Kwon (2016) US	Phenomenological approach qualitative approach	Semi-structured and open-ended interview	Purposeful sampling 5 mothers 1 fathers	South Korean parents	Autism Spectrum Disorders	<ul style="list-style-type: none"> • Used religion or spiritual support. • New culture, prejudice and limited English proficiency were challenges.
16.	Lai (2004) Canada	Qualitative design	Semi-structured interview	Purposeful sampling 10 mothers	Chinese parents	Developmental Delay; Intellectual Disability; Hearing Impairment; and Visual Impairment.	<ul style="list-style-type: none"> • Adapting to a new culture was a challenge, • Limited English proficiency impeded parents' involvement in their children's education.
17.	Lee (2016) US	Qualitative design	In-depth and semi-structured interview	Purposeful sampling 7 mothers	Korean parents	Developmental Delay; Intellectual Disability; and Autism Spectrum Disorder	<ul style="list-style-type: none"> • Support from other family member helped in coping. • Limited English proficiency reported as a challenge.

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
18.	Luong (2009) US	Qualitative design	Open-ended question interview	Purposeful sampling 8 mothers 1 father	Southeast Asian parents	Autism Spectrum Disorder	<ul style="list-style-type: none"> Reported experiences of social isolation Spiritual coping were reported by parents.
19.	Narayan (2015) US	Qualitative design	Semi-structured interview	Purposeful sampling 8 mothers 5 fathers	Asian Indian parents	Intellectual Disability	<ul style="list-style-type: none"> Parents reported financial challenges, profound social isolation, and a lack of family and social support. Lack of cultural awareness among professionals
20.	Shtutman, (2016) US	Interpretive phenomenological analysis design	Open-ended interview	Purposeful sampling 6 mothers	Russian parents	Physical and/or mental disability	<ul style="list-style-type: none"> Language barriers, social stigma and adaption to a new culture, and struggling when navigating health and school system as challenges
21.	Sritharana & Koola, (2019)	Not specified	Narrative review	21 qualitative studies	Different culture background	Autism Spectrum Disorders	<ul style="list-style-type: none"> Complicated health system and long waiting lists are barriers for immigrant parents.
22.	Stevens (2010) Australia	Ethnographic design	Survey	Purposeful sampling 17 respondents	Lebanon, Vietnam, Croatia, East Timor, the UK, NZ, Turkey, the Philippines, and China	Not specified	<ul style="list-style-type: none"> Migrant parents were doubly socially isolated due to immigrant status and carer responsibilities.

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
23.	Su (2008) US	Phenomenology approach	In-depth interview	Purposeful and snowball sampling 4 mothers 4 fathers	Taiwanese parents	Down's Syndrome and Autism Spectrum Disorder	<ul style="list-style-type: none"> Experienced societal prejudice Resilience came from diverse sources such as socioeconomic status, values, personality characteristics and belief systems.
24.	Wang (2012) US	Qualitative design	Semi-structured interview	Purposeful sampling 4 mothers 2 fathers	Asian parents	Autism Spectrum Disorder	<ul style="list-style-type: none"> Coping strategies included searching for knowledge related to their child disability, and looking for new resources such as attending support groups. Parents growing stronger from having a child with a disability.
25.	Wathum-Ocama (2002) US	Qualitative design	Semi-structured interviews, examination of students' records, and participant observation	Criterion-based sampling 7 mothers 6 fathers	Hmong parents	Deaf and hard of hearing children	<ul style="list-style-type: none"> Limited English proficiency was an impediment to the involvement of parents in their child's school system

Study ID	First Author/ year/ country	Design	Method	Sample	Country of origin of the subjects	Type of child's disability	Key findings
26.	Zechella (2016) US	Qualitative design	Open-ended interview	Purposeful sampling 8 mothers 7 fathers	Asian Indian parents	Developmental disability	<ul style="list-style-type: none"> • Use of community resources and social support made parents feel less lonely. • Parents reported positive aspect of caring such as understanding deeper purpose in life and overcoming marital differences. • Parent with flexible personality who utilized a “1 day at a time” approach was more resilient. • parents who had high income, unconditional family support, speaking English fluently, more educated, and employed in primarily professional jobs were resilient. •

The subthemes identified during the data reduction phase were then independently placed by the researcher into matrices around the themes: Parental Challenges, Parental Coping, or Resiliency factors associated with parental coping. The researcher referred back to the primary source as needed to verify context and help clarify the subthemes. A master list was generated and the final placement of each subtheme into a theme was determined through the researcher and the supervisory team's consensus. The researcher then synthesized the important elements and conclusions for each theme into an integrated summation. Themes and sub-themes were generated from the findings which reflected the aims of the review (see Table 3).

Table 3

Generated Themes and sub-themes

Theme	Subthemes
Challenges of raising children with disabilities	Language barriers; financial hardship; services utilisation challenges; poor adaptation to new culture; stigma related to mental illness; and discrimination, and social isolation.
Coping strategies used by immigrant parents of disabled children.	Problem-focused coping; avoidance coping; spiritual coping; and social support.
Resiliency factors associated with parental coping	Resiliency protective factors such as social and emotional support, instrumental support, personality traits and faith.

2.4 Findings

2.4.1 Data presentation

Seventeen reviewed studies were conducted in the United States (US), four in the United Kingdom (UK), three in Canada and one in Australia. There were 287 participants

with 190 mothers, 53 fathers and 27 service providers in the 26 reviewed studies. All immigrant parents included in this review had English as a second language. Immigrant parents included in this review were Russian, Indian, Mexican, Somali Bantu, South Asian, Taiwanese, South Korean, Haitian, Latin American, Pakistani parents and Asian population that was not specified.

2.4.2 Challenges of Raising Children with Disabilities

2.4.2.1 Language barriers

Two qualitative studies (one from the United States [US], one from Canada) using semi-structured interviews revealed that language barriers is a challenge for immigrant parents in schools (Lai & Ishiyama, 2004; Wathum-Ocama & Rose, 2002). Parents perceived the special school's English-speaking teachers had limited understanding of their needs. Interpreting services were only provided in occasional formal meetings with school staff, not in day-to-day interaction (Lai & Ishiyama, 2004; Wathum-Ocama & Rose, 2002).

In the healthcare context, immigrant mothers in the US perceived limited English proficiency as the greatest barrier in forming meaningful partnerships with healthcare professionals (Lee & Park, 2016). Parents were perceived by healthcare professionals as passive in accessing health services. Parents were perceived as unable to attend to the child's needs or provide appropriate care (Lee & Park, 2016). A phenomenological study conducted in the US on Russian Jewish immigrant mothers found the mothers struggled in navigating health and school systems due to limited English proficiency. Even for immigrant parents who were proficient English speakers, they considered many jargons used by healthcare professionals to be incomprehensible (Shtutman, 2016). Another qualitative study found parents perceived a lack of written communication in their native language as a challenge in navigating the healthcare system (Blanche, Diaz, Barretto, & Cermak, 2015).

2.4.2.2 Financial hardship

Khanlou and colleagues (2015) found that financial hardship was a crucial challenge among fathers. They had inadequate employment opportunities which reduced family income and sometimes resulted in poverty. Asian Indian immigrant mothers living in the US reported high costs of raising a child with a disability such as assessment and specialist fees. They quitted their jobs and lost their income because they needed to devote more time to their children with disabilities (Narayan, 2015).

Mexican immigrant mothers raising children with disabilities in the US reported that they faced financial crises because of medical care payment for their children. This difficulty was intensified by their undocumented status as they were not eligible for assistance such as health insurance (Alvarado, 2004).

2.4.2.3 Services utilisation challenges

In the US, Somali Bantu immigrant parents shared challenging experiences in accessing services for their children with disabilities, particularly in the school and healthcare systems. The immigrant parents reported that they did not receive the level of care and sensitivity which would have been expected within their culture (Beatson, 2013). Lack of cultural awareness among health professionals was also voiced by Asian Muslim immigrant parents raising children with Autism living in the US. The parents avoided utilising healthcare services because they perceived European-American professionals as being cold and abrupt, spending less time interacting with them, and showing little or no interest in their cultural background (Jegatheesan, Fowler, & Miller, 2010). Complicated health system and long waiting lists were reported as barrier for immigrant parents (Sritharana & Koola, 2019). Other immigrant parents reported that they tried to disengage from the health and social services because they felt that the services were culturally inappropriate (Bradby et al., 2007; Narayan, 2015).

Khanlou, Haque, Sheehan and Jones (2015) explored the perspective of Canadian service providers (social work, health services, legal services, and community services) on the challenges that immigrant mothers with children with disabilities encountered in accessing social support and services. Service providers stated that immigrant mothers did not use the available services because they were not able to fill out the comprehensive assessment forms that were required from the service organizations. Although the majority of mothers appreciated the services once they used them. Some immigrant parents did not aware of their right to access those free available services (Khanlou, Haque, Sheehan, & Jones, 2015)

Transportation was found to be a challenge. Attending medical appointments for a child with a disability was a challenge due to inconvenient public transportation. This is of special relevance as new immigrant families often settled in peripheral suburbs where the rent was cheaper, but health and social services were mainly located in the city centre (Khanlou, Haque, et al., 2015; Khanlou, Mustafa, et al., 2015).

2.4.2.4 Poor adaptation to a new culture

Shtutman's (2016) study found cultural differences were confusing to immigrant parents. For instance, to smile and talk to a stranger is considered normal behaviour in the US but not for Russian Jews. Immigrant families found it difficult to adapt to their host country's norms and customs. As a result, they reported dissimilation to the dominant culture (Shtutman, 2016). South Asian parents living in the UK viewed adapting to a new culture as an additional burden which compounded the existing burdens of raising a child with a disability (Heer, Larkin, & Rose, 2015).

2.4.2.5 Stigma related to mental illness

Bradby and colleagues (2007) explored the experience of immigrant parents in the UK using Child and Adolescent Mental Health Services. Parents reported feeling ashamed

of their children's mental health problems. They were concerned about gossip among their own community. Mothers of children with Attention Deficit Hyperactivity Disease (ADHD) living in the US similarly stated that they felt stigmatised. They worried that they would bring shame to their family if they sought help from psychiatrists or psychologists (Al-Azzam, 2011).

Three studies found immigrant parents reported feeling stigmatised due to the challenging behaviours of their children with disabilities, such as violent outbursts. These behaviours were considered culturally inappropriate and were not tolerated by their local community. This stigma resulted in families' tendency to hide their children at home and to delay help-seeking (Blanche et al., 2015; Fox, Aabe, Turner, Redwood, & Rai, 2017; Ijalba, 2016). Parents were isolated from their extended family and community (Blanche et al., 2015). Khanlou and colleagues (2015) found immigrant parents felt strongly that they were social outcasts not only by the community, but by their families who tended to blame them for their child's condition.

2.4.2.6 Discrimination

Immigrant parents reported experiencing discrimination in both their home and host countries (Su, 2008). A study of Taiwanese families living in the US found that one of the main reasons for their immigration was to find a place which would be more accepting of their children with disabilities. However, they were shocked to find that their children were also not being accepted and being rejected in multiple situations by their new host country (Su, 2008). Similarly, South Korean immigrant parents living in the US reported feeling discriminated by their own community in the host country due to their child's disability (Kwon, 2016). South Asian parents in the UK raising children with mental illnesses such as ADHD, Autism and disruptive antisocial behaviour reported discriminatory treatment in

education, health and social care. They attributed this discrimination as being based on ethnicity, due to their status as a minority group (Bradby et al., 2007).

2.4.2.7 Social isolation

Stevens (2010) explored the experience of immigrant parents from different countries such as Lebanon, Vietnam, Croatia, East Timor, Turkey, the Philippines, and China who migrated to Australia and caring for children with disabilities. Immigrant parents expressed that there was no one they could rely on for help and emotional support. They experienced a sense of isolation due to their migrant status and carer responsibilities (Stevens, 2010).

Other studies also found immigrant parents experienced loneliness and struggled without support system (Shtutman, 2016), even though they lived with their extended families in the host country. They reported social isolation because of not being accepted by their extended family due to raising children with disabilities (Narayan, 2015). Southeast Asian parents reported that caring for their children with disabilities could be physically and psychologically demanding as well as time-consuming, all of which restricted their social activities (Luong, Yoder, & Canham, 2009).

2.4.3 Coping Strategies Used by Immigrant Parents of Children with Disability

2.4.3.1 Problem-focused coping

Haitian immigrant parents raising children with disabilities in the United States tended to use problem-solving coping strategies. They identified the challenges and then attempted to minimise the negative outcome. The more educated parents tended to find direct solutions to problems, while those who were less educated developed ways to avoid factors that might trigger their child's challenging behaviours, particularly in social gatherings (Gregoire, 2011). Wang and Casillas (2012) reported the experiences and coping mechanisms of Mandarin-speaking parents raising children with disability in the US.

Parents confronted their challenges by searching for knowledge related to their child's disability and looking for appropriate community resources (Wang & Casillas, 2012).

2.4.3.2 Avoidance coping

Some parents reported that they avoided expressing their concerns regarding their child's difficulties because they worried that stories about their problems would leak back to their village of origin (Blanche et al., 2015). South Asian immigrant parents claimed that they avoided social gatherings because they felt their own community did not understand their child's condition. Parents avoided social events because of the discomfort with having their child's challenging behaviours judged by others (Luong et al., 2009).

2.4.3.3 Spiritual coping

Southeast Asian immigrant parents in Luong and colleagues' (2009) study sought religious support such as praying at home to maintain a sense of hope. Somali immigrant parents raising children with autism expressed that their faith was a source of comfort that helped them to cope. They described Allah-God as being in control of their lives and they voiced gratitude and trust in Allah's plan for the future (Fox et al., 2017). Similarly, South Korean immigrant parents explained that religion and spirituality were powerful coping mechanisms or a source of comfort, peace, and hope (Kwon, 2016). Pakistani parents who lived in the UK believed that their child's disability was from God. They sought help from religious sources, such as visiting temples, which was considered an acceptable and helpful aid to manage their child's disability (Croot, Grant, Mathers, & Cooper, 2012).

2.4.3.4 Social support

Mothers who primarily shouldered the care burden for their child with a disability concurred that support from other family members, especially from spouses, played a critical role in their coping. When fathers accepted their child's disability and supported their partners, the mothers were more able to comfortably reach out to other informal social

support groups and developed relationships with other parents with a similar situation (Lee & Park, 2016).

Support groups that bring together families facing the same situation were found to be effective. Parents appreciated the opportunity to develop supportive relationships with other immigrant families raising children with disabilities. Support groups provided parents not only with information but also with encouragement, support, reassurance, optimism, and hope (Khanlou, Haque, et al., 2015; Lee & Park, 2016). A quantitative study in the US among Indian immigrant parents of children and adolescents with developmental disabilities found a negative correlation between parents' perceived quality of social support and their overall stress levels. Perceived quality of social support facilitated their coping thus reduced their stress levels. The participants ranked their spouse as their most significant source of support followed by support groups and friends. Only 18.2% of these parents perceived support provided by doctors as excellent and 3% of parents perceived healthcare providers and nurses as an excellent source of support (John et al., 2016).

Immigrant families also used social support services such as schools, social workers, and interpreting services to target their specific problems (Croot et al., 2012). Asian Indian immigrant parents in the US stated that when they were able to access resources in the school or in the community, they felt less lonely and their needs were being met (Zechella & Raval, 2016).

2.4.4 Resiliency factors associated with parental coping

Four studies explored resiliency factors associated with parental coping. The findings revealed that immigrant parents who received social and emotional support from their family seemed to be resilient. Other parents who received instrumental support such as being employed in a professional job, speak English fluently, had a high income, had driving license, or being more educated appeared more resilient (Heer et al., 2015; Su,

2008; Zechella & Raval, 2016). A combination of two or more of these resources led to more resilient parents (Su, 2008). Service providers in Khanlou, Haque, et al's (2015) reported that parents who received social, instrumental, and emotional support from their families and from care providers seemed to be more resilient.

Other parents reported that their personality traits and faith were the vital factors that contributed to their resilience. Although these parents could not speak English, and had low socioeconomic status, their resilience was similar to other parents. This was because those parents had optimistic and flexible personalities and they have their own religious beliefs and often involved in their faith communities (Su, 2008; Zechella & Raval, 2016).

2.5 Discussion

This review found immigrant parents raising children with disabilities had key challenges which included limited English proficiency, and services utilisation. Language barriers limited the communication and negotiation between the immigrant parents and the healthcare providers. This created a barrier to access services which were available for their children with disabilities in the host country.

In contrast to the beliefs that service providers should be supportive to immigrant parents, this review found that parents perceived discrimination by their service providers. Immigrant parents perceived poor interaction with healthcare professionals due to the providers' lack of cultural awareness to take care of immigrant parents. Complicated healthcare system and long waiting lists were reported also as barrier for immigrant parents in this review. Lack of cultural awareness among service providers and complicated healthcare system were regarded by parents as the core challenge which hindered the utilisation of services (Jegatheesan et al., 2010). However, Jegatheesan et al's (2010) findings were from immigrant parents' perception which could be a subjective view. Other

studies conducted to measure cultural awareness of healthcare professionals who provided care to those parents revealed lack of training in providing culturally sensitive care (Grandpierre, et al., 2018; Lindsay, et al., 2012).

Financial hardship was reported by most of the immigrant parents who lived in the US. That might be related to healthcare finance in the US (Kaiser Family Foundation, 2019). Not all immigrants who live in the US are eligible for public health coverage such as Medicaid. Further, immigrant parents explained that due to the care demands for a child with disability, they needed to stay at home or worked part time, thus losing income (Khanlou, Mustafa, et al., 2015). However, in other countries such as UK and Canada, immigrants are eligible for the public healthcare services, which means that they do not have to pay for most healthcare and hospital services (WHO, 2018). This might be a reason that they did not mention financial hardship.

Discrimination was reported by immigrant parents who live in US and UK but not in Australia. This might be related to the cultural context of the US and UK populations in accepting diverse culture in their countries. Immigrants might experience discrimination for different reasons. This can be due to their characteristics such as ethnicity and race, but also factors such as having a foreign accent or foreign qualifications (Szaflarski & Bauldry, 2019). The immigrant population in the US and UK is diverse, not only in terms of their national and ethnic origins, but also with regard to their economic and educational backgrounds. These differences will affect their experiences of discrimination (Fernandez-Reino, 2020). For example, a study has shown that immigrant groups who are from less developed countries or from minority culture and ethnic background are more likely to experience discrimination than those who are from developed countries (Dancygier and Laitin, 2014). Immigrant parents in the present literature review attributed this

discrimination as being based on ethnicity, due to their status as a minority group.

Healthcare providers need to understand and to provide viable and equal care for those parents and their children.

It is well documented in the literature that immigrant families in different countries are facing very similar challenges such as language challenges, financial challenges and social isolation (Hurtado-de-Mendoza, Gonzales, Serrano & Kaltman, 2014; Woodgate et al., 2017). However, immigrant parents raising children with disabilities are facing extra challenges on top of the usual challenges. For example, on top of language barrier, they reported being isolated due to embarrassment caused by their children's disruptive behaviour in the public. They used healthcare services more than other immigrant parents due to children's health status. Thus they experienced more difficulties in navigating health system than immigrant parents without children with disabilities. The pressures of adapting to a new culture, along with taking care of children with disability, increase the burden of care for these immigrant parents. Healthcare professionals need to understand and be sensitive to the needs of these parents and provide culturally appropriate support and care.

In the present review, 26 studies were related to immigrant parents' perspectives. Only one study explored the service providers' perspective. Children with disability are most likely utilise healthcare services such as hospitals and child health centres due to their ongoing complex healthcare needs (Khanlou, Haque, et al., 2015). Service providers may have unique perspectives on the care that immigrant families should receive. Future studies should address this gap.

This review found that immigrant parents used various coping strategies to manage their caregiving challenges. On top of seeking social support, some immigrant parents identified religion, prayer, and spirituality as a coping mechanism that provided them with comfort or hope (Crook et al., 2012; Fox et al., 2017; Kwon, 2016; Luong et al., 2009).

Literature suggested that religious beliefs can shape a person's psychological perception of pain or disability as they create a mindset that enables the person to relax and allow healing on its own (Joshi, Kumari, & Jain, 2008). These behaviours include trying to find a lesson from God in the stressful event, doing what one can do and leaving the rest in God's hands, and seeking support from church members (Joshi et al., 2008). This review has similar findings which highlighted the importance of spiritual support and care.

Having a support system of family and friends who they could spend time with and rely on was a vital factor that helped immigrant families to manage their challenges (Khanlou, Haque, et al., 2015). Additional support from healthcare professionals such as emotional support and information support for caregivers have also been reported to enhancing caregivers' abilities in managing their challenges (Leow & Chan, 2017). Parental support group may also help to enhance peer support.

The cultural values and beliefs of the parents' home country may affect their perceived challenges, coping process, and even access to healthcare services. Most immigrant parents do not realize that access to health and education are their basic rights and, therefore, do not actively seek the resources they need for their children. Parents' cultural beliefs and values may also influence how they access available services, follow up with treatment, and how they view their child's disability. In some cultures, disability is associated with stigma and a sense of shame (Koschorke, et al., 2017). If this stigma is not adequately addressed, some parents may avoid access to healthcare and/or social services and may face social isolation and social exclusion. Cultural values and beliefs may also affect parental coping process such as social support, faith and belief in God. The value of extended families for social support was often described by parents as important. Thus it is not only the immigration status that impacts parental experience in raising children with

disability (e.g. language barrier, adapt to a new culture, or navigate new system) but also immigrant parents' cultural values and beliefs.

This review found that personality traits such as flexible, optimistic personality, and parents' faith are protective factors that allowed immigrant parents to adapt well and be resilient. Resilience has a positive impact on decreasing caregivers' burdens in studies relating to chronic diseases. As caregivers' resilience increases, their caregiver burden decreases (Rosa, Bagnasco, Aleo, Kendall, & Sasso, 2017; Scott, 2013). These findings highlight the importance of interventions that enable healthcare professionals to foster greater resilience among immigrant parents of children with disabilities. Such interventions mitigate parents' burdens.

2.6 Limitations

This review has limitations. The small sample size of some studies limited the generalisability of the findings. For examples, Alvarado (2004) explored the experience of two immigrant mothers in raising their children with disabilities. In a quantitative study, John, Bower & McCullough (2016) recruited thirty-three immigrant parents to examine their stressors and perceived quality of social support in raising their children of disabilities. In Jegatheesan et al.'s (2010) study, the presence of a researcher during the observation might have influenced the participants' behaviour. In Stevens' (2010) study, the author is an immigrant mother who has a child with a disability which might affect the objectivity of the study results. In this review, immigrants were examined as one category. Immigrants are not a homogenous group. Further, the reviewed studies were conducted in four western countries and all in English-speaking countries. Each country has own culture and healthcare policies. This will affect the generalizability of the review results to other countries or healthcare setting. Further, there was no ethical issue reported in the reviewed

studies for participants with a language barrier, their understanding of confidentiality and protection of individual privacy.

2.7 Literature Gap

This review found only one quantitative study and 24 qualitative studies. Mixed methods design using quantitative and qualitative approaches is needed because.....Larger sample size is recommended in future studies to address this phenomenon comprehensively. To have an in-depth understanding of immigrant parents' challenges in service utilisation, future research could be conducted in more countries, like Australia which has a large population of immigrants. Immigrant parents raising children with disabilities in Australia may have different parental challenges, coping and resiliency when compared to the US, Canada or UK due to different health, social and education systems. Future studies should also include the perspective of service providers because.....

2.8 Summary

This integrative review synthesized the literature on challenges, coping strategies, and resilience in caring for children with disabilities among immigrant parents. The findings of the review provided the direction and informed the methodology of the current study. Next chapter will present the research methodology and methods used to conduct the current study.

Chapter 3: Research Methodology and Methods

3.1 Introduction

This chapter discusses the methodology and methods of the current study. This study adopted the sequential explanatory mixed-methods approach with two phases. Phase one was a quantitative survey and phase two was a qualitative interview. This chapter explains the mixed-methods approach and presents the justification for using the sequential explanatory mixed-methods approach. The study venues, sampling approach, instruments and ethical considerations are discussed in detail. The quantitative and qualitative data collecting methods at phase one and two are explained. The data analysis procedures for both phases are then discussed.

3.2 Research Methodology

Research methodology is the overall philosophical approach to the research design from its theoretical underpinning to the collection and analysis of data (Creswell, 2009). The main research methodologies include a quantitative approach associated with the positivism paradigm, a qualitative approach associated with the constructivism paradigm and a mixed-method approach associated with the pragmatism paradigm (Creswell, 2009).

A paradigm is a way of describing a worldview that is informed by philosophical assumptions about the nature of social reality, ways of knowing, ethics and value systems. It is related to the abstract beliefs and principles that shape how a researcher sees the world and interprets and acts within that world. It also influences decisions regarding the research process, including the choice of methodology and methods (Kivunja & Kuyini, 2017, p. 26).

A paradigm comprises epistemology, ontology, axiology and methodology (Guba & Lincoln, 2005). Epistemology is about ways of knowing—that is, how we know and what we know. It enquires into the nature of knowledge and truth. It asks about the source of knowledge and how to know whether something is true or not (Guba & Lincoln, 2005). Ontology is about the nature of social reality—that is, what we believe about the nature of reality. It relates to whether we believe there is one verifiable reality or multiple, socially constructed realities. Axiology refers to ethics and value systems—that is, what we believe is true (Guba & Lincoln, 2005). Together, these paradigmatic aspects help to determine the assumptions and beliefs that frame researchers' view of a research problem, how they investigate it and the methods they use to answer the research questions.

Paradigms are associated with certain methodologies (Creswell, 2013). Each paradigm is undergirded by specific assumptions. The choice of paradigm for a research study implies that the research will be nested in an epistemology, ontology and axiology, and that these elements will guide the researcher towards a particular methodology. There is no right or wrong paradigmatic framework. It is the researchers' choice to determine their own paradigmatic view and how it informs their research methodology to best answer the question under study (Kivunja & Kuyini, 2017).

3.2.1 Quantitative approach

Quantitative research is the dominant research approach used in medicine, science and nursing. It is defined as a systematic process used to gather information that has been measured by an instrument. Instruments are used to transform information into numbers. Quantitative research involves concepts that can be measured and turned into numbers (quantifiable concepts). It examines phenomena through the numerical representation of observations and statistical analysis (Esperón, 2017). Examples of quantitative data

collection methods include various forms of surveys, such as online surveys, paper surveys, structured interviews, online polls and systematic observations.

Quantitative research is associated with the post-positivism paradigm, with the philosophy that the causes determine the effects or outcomes. The problems studied by post-positivists reflect the need to identify and assess the causes that influence outcomes. Post-positivism is a reductionistic approach in that the aim is to reduce the ideas into small, discrete sets to test, such as the variables that include hypotheses and research questions (Creswell, 2013).

The knowledge that develops through a post-positivism lens is based on careful observation and measurement of objective reality. Thus, developing numeric measures to observe and study the behaviour of individuals becomes paramount for post-positivists (Panhwar, Ansari & Shah, 2017). A researcher can test, verify or refine laws or theories that govern the world. A researcher begins with a theory, collects data that either supports or refutes the theory and then makes necessary revisions and conducts additional tests (Panhwar et al., 2017).

The main strength of the quantitative methodology is that it provides numeric estimates for large sample sizes. These numeric data are verifiable and comparable among different communities in different locations (Choy, 2014). The findings of quantitative studies may be generalised to the population about which information is required. The main limitation of a quantitative design is that it fails to provide an in-depth description of the experience of the affected population.

3.2.2 Qualitative approach

Qualitative research is defined as a process of understanding based on distinct methodological traditions of inquiry that explore a social or human issue (Walsh, 2017). Qualitative research seeks to understand an individual's perspectives and explores life

experiences. Examples of qualitative methodologies that are employed in healthcare research include grounded theory, phenomenology, ethnography and the qualitative descriptive method (Bradshaw, Atkinson & Doody, 2017).

Qualitative research is associated with the constructivism paradigm. It is an inductive process that develops conclusions and generalisations from specific observations and builds ideas or theories from the ground up. The crux of constructivism is to understand complex relationships rather than to explain a single relationship (Creswell, 2013).

In this paradigm, the researcher acts as the research instrument. The researcher seeks to answer questions about how or why a phenomenon occurs. However, there is no attempt to change the research situation or control it. The aim is to understand as much as possible about the participants' views of the situation being studied. Thus, constructivist researchers not only address the processes of interaction among individuals but also focus on the specific contexts in which people live and work to understand their historical and cultural settings (Panhwar et al., 2017).

In qualitative methods, the participants are purposefully recruited based on their familiarity with the phenomenon. Data are generally collected via one or a combination of the following methods: interviews, observation and document/photograph review (Kabir, 2016).

The main strengths of a qualitative design are that it provides rich and detailed information about the affected population and an in-depth analysis of the effect of certain phenomena. The limitations include that the data collected may not be objectively verifiable and that the data collection process can be very time consuming and can last for months or even years (Choy, 2014).

3.2.3 Mixed-methods approach

The mixed-methods approach has been developed to overcome the limitations of quantitative and qualitative designs. This approach is associated with the pragmatic paradigm. Pragmatism is problem centred and real-world practice centred. Instead of focusing on methods, researchers focus on the research problem and use all approaches available to understand the problem. The approach is not committed to any one philosophy or reality. In pragmatism inquiry, researchers are free to choose research methods that fit their aims and objectives. Pragmatists use more than one approach for collecting and analysing data (e.g., quantitative and qualitative) (Creswell, 2013).

For mixed-methods researchers, pragmatism opens the door to multiple methods and different worldviews, assumptions, forms of data collection and analysis. Pragmatism is a useful paradigm that combines two or more methodological strategies or techniques simultaneously or sequentially, usually quantitative and qualitative, into a single research study (Kivunja & Kuyini, 2017).

Migiro and Magangi (2011) discussed the rationale and advantages of mixing quantitative and qualitative methods in a single study. The rationale goes beyond the notion of triangulation. In mixed-methods design, the quantitative and qualitative methods complement each other and the results from one are used to elaborate on the results from the other. This allows researchers to undertake a complete analysis of the research problem and to access parts of the phenomena of interest that cannot be accessed using one method.

Thus, a mixed-methods design can be used to answer a broader and more comprehensive range of research questions. It can be used to overcome the weaknesses in a single method design and to strengthen the study. This approach can also provide stronger evidence for a conclusion through convergence and corroboration of the findings and produce complete knowledge necessary to inform theory and practice (Migiro & Magangi,

2011). There has been an increase in mixed-methods studies in healthcare research. This is because mixed-methods studies can address some research questions more comprehensively than using a quantitative or qualitative method alone (Tariq & Woodman, 2013).

This study adopted the pragmatism approach with a mixed-method design. This was because integrating qualitative and quantitative approaches enabled the researchers to obtain extensive and in-depth findings on the relationship between challenges, coping and resilience of immigrant parents raising children with disabilities.

3.2.4 Types of mixed-methods design

In mixed-methods designs, qualitative and quantitative data can be collected either sequentially or concurrently. In sequential studies, one data collection method follows the other, whereas in concurrent studies, the qualitative and quantitative data are collected at the same time (Kivunja & Kuyini, 2017). The decision about the implementation sequence is determined by the nature of the study question and the rationale for collecting the data. For example, when qualitative and quantitative data are being collected for confirmation, it may be possible to collect the data at the same time (concurrently). When interviews are intended to provide insight into survey findings, they are generally conducted after the analysis of the survey data (sequentially).

There are three major types of mixed-methods design: convergent parallel mixed methods, explanatory sequential mixed methods and exploratory sequential mixed methods (Creswell, 2013).

3.2.4.1 Sequential explanatory design

In the sequential explanatory design, quantitative data is usually collected during the first phase, followed by qualitative data in the second phase. Qualitative data from the second phase is used to explore further or explain the quantitative data from the first phase.

Further, the results of the quantitative phase can be used to guide the purposeful sampling of the qualitative phase. The findings from each phase are analysed separately first and then integrated into the interpretation phase. The final discussion of the study brings the results of the two phases together. A sequential explanatory mixed-methods design is useful when interpretation or explanation of relationships in a phenomenon is required. The main strength of this design is its straightforward nature; it is easy to implement because the steps fall into clear, separate phases. The main weakness of this design is the length of time involved in data collection across the two phases (Creswell, 2013).

3.2.4.2 Sequential exploratory design

In contrast to a sequential explanatory design, a sequential exploratory design is characterised by initial qualitative data collection and analysis followed by quantitative data collection and analysis. The primary approach is the qualitative method. The results of both phases are integrated after the data of each phase is analysed. The main purpose of sequential exploratory design is to use themes generated from the qualitative phase (the first phase) to drive the development of a quantitative instrument that can further explore the research problem (Aratangy & Zerger, 2014). The main strengths of this design are its straightforward nature and clear steps. The main weakness of this design is the length of time it takes to complete the data collection and analysis of each phase separately (Aratangy & Zerger, 2014).

3.2.4.3 Convergent design

The convergent design is characterised by the concurrent collection of qualitative and quantitative data to confirm and cross-validate findings from both methods. This helps to offset the weaknesses of using one method. Both methods are of equal importance. Usually, the integration of results occurs in the interpretation phase. Since the data collection for both methods are conducted at the same time, the shorter data collection

duration is a strength of this approach. A weakness of this design includes the great effort and expertise required to study the phenomenon adequately and to manage a situation in which quantitative and qualitative results contradict each other (Creswell, 2013).

3.2.4.4 Study design

To gain a holistic perspective of the experience of immigrant parents raising children with disabilities, the present study used the sequential explanatory design. The first phase of the study was a quantitative design. In this phase, the researcher examined the challenges, coping and resilience of immigrant parents of children with disabilities using a quantitative survey. The survey was completed by the immigrant parents raising children with disabilities. The data generated from the survey guided the purposive sampling of the second phase, which was an individual semi-structured interview. The data from the first phase also helped to refine the interview questions.

The second phase of the study aimed to understand immigrant parents' challenges and their experiences in coping and resilience from both the parents' and service providers' perspectives. Literature has highlighted the challenges, coping and resilience of immigrant parents from the parents' perspectives (Beatson, 2013; Bradby et al., 2007; Lee & Park, 2016; Narayan, 2015). Although immigrant parents realised their challenges and the existing services, gaps in access to essential services remain rampant. To ensure an in-depth and comprehensive understanding of this topic, we also investigated service providers' perspectives on services accessibility and the challenges faced by immigrant parents in raising children with disabilities. Thus, both immigrant parents and service providers were interviewed in phase two. The qualitative data helped to explain and understand the quantitative data of the first phase. The findings of both phases were integrated into the interpretation phase.

The sequential explanatory mixed-methods design was the appropriate design for this study. The survey conducted in the first phase enabled the researcher to obtain perspectives from a larger population. The qualitative interviews in the second phase enabled the researcher to gain an in-depth understanding of the immigrant parents' challenges, coping and resilience in raising their children with disabilities from both the parents' and providers' perspectives. The qualitative findings helped to interpret the quantitative results. Figure 2 illustrates the process of the study.

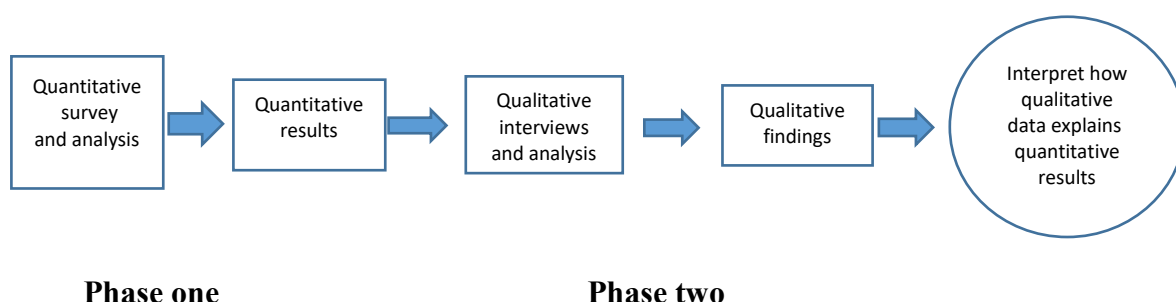


Figure 2. Sequential explanatory mixed-methods design in this study.

3.2.4.5 Study venues

This study was conducted in seven centres of the National Disability Insurance Scheme (NDIS), New South Wales (NSW) across two cities: Sydney and Newcastle. The researcher approached 11 centres recommended by the NDIS in Sydney and Newcastle, as these centres provided services for a large number of immigrant families who were considered representative. Of the 11 centres approached, a total of seven - four centres in Newcastle and three centres in Sydney, agreed to participate in the current study.

3.3 Phase One: Quantitative Survey

3.3.1 Aim

To examine the challenges, coping and resilience of immigrant parents of children with disabilities.

The objectives are to:

- explore parental challenges
- examine parental coping strategies
- examine parental level of resilience
- investigate the relationships among challenges, coping strategies and resilience.

3.3.2 Methods

A multi-centred cross-sectional survey was employed. A cross-sectional study aims to describe the overall picture of a phenomenon or problem by surveying a cross-section of a given population at one moment in time (Jesson, 2001). The cross-sectional survey method allows researchers to collect a large amount of data from multiple sites at one time point. It is relatively inexpensive, can be performed in a short time frame and permits several outcomes to be measured together (Levin, 2006). This method allows specific outcomes of interest to be assessed (in the present study—parents’ challenges, coping and resilience). Thus, it is a suitable method for phase one study. The researcher collected data from seven NDIS centres at the same time to assess three variables using questionnaires: immigrant parents’ challenges, coping and resilience. Further, it allows the researcher to collect a large amount of data in a relatively short time (in the present study—a six-month period).

3.3.3 Sampling

A convenience sampling approach was used to recruit participants who represent the target population of interest to this study. It is one of the most popular forms of non-probability sampling, in which participants are selected based on convenience in terms of accessibility and availability to the researcher (Houser, 2011). However, convenience sampling can be prone to researcher bias (Sharma, 2017). Participants were recruited based on the judgement of the researcher that might introduce researcher biases, especially when compared with probability sampling techniques such as random sampling that are designed to reduce such biases. While random sampling is the preferred sampling method which characterised by unbiased and high representativeness of the population, it was not possible to apply in the current study due to difficulty gaining access to a list of a larger population, time consuming and high costs (Sharma, 2017). Thus, convenient sampling was used in the current study.

In the present study, the participants were recruited based on the following inclusion and exclusion criteria.

3.3.4 Inclusion criteria

Parents (mothers and/or fathers) who:

- immigrated from their country of birth to Australia regardless of their immigration period,
- are willing to participate in the study regardless of their age, education level, socioeconomic status (SES) or cultural background,
- have one or more children who are < 18 years old with one or more disabilities,
- can read, speak or understand basic English (fifth-grade level).

3.3.5 Exclusion criteria

Individuals who:

- are not immigrants,
- do not have a child with disability,
- have > 18 years old adult children with disability,
- cannot read, speak, or understand basic English (< fifth-grade level).

3.3.6 Sample size calculation

The participants were recruited from monthly support group meetings and activities that occurred at the seven NDIS centres. The sample size calculator (Calculator.net, 2018) was used to estimate a study sample size using correlation as the basis for statistical analysis. Approximately 12 parents attended each monthly session (about 504 in six months). We expected that about 50% of the parents would be eligible for the study (about 252 in total). By convention, a medium effect size of 0.5 was expected. With a confidence level of 95% and α error probability of 0.05, 132 participants would be adequate (Polit & Beck, 2012).

During the recruitment period, a total of 504 parents were approached. After checking their eligibility based on the inclusion and exclusion criteria, 237 of them were found to be eligible and were invited to participate in the study. A total of 134 returned the questionnaire. The response rate was 56.5%, which was considered satisfactory.

3.3.7 Instruments

The following instruments were used to measure parental challenges, coping and resilience: the Zarit burden interview scale (ZBI), the family crisis oriented personal evaluation scale (F-COPES) and the Connor-Davidson resilience scale (CD-RISC 10). The

researcher has obtained permission to use the study instruments from their authors (see Appendix C).

3.3.7.1 ZBI scale

Parental challenges were measured in the current study using the 22-item ZBI (see Appendix D) (Zarit, Reever & Bach-Peterson, 1980). The ZBI was designed to assess the challenges experienced by family caregivers of older people and persons with disabilities. It has been used to evaluate the challenges faced by caregivers of children and adolescents with chronic illnesses such as sickle cell anaemia, haemophilia, inborn errors of metabolism and cancer (Javalkar et al., 2017; Macedo, da Silva, Paiva & Ramos, 2015; Toki et al., 2010). Questions have been revised for studies related to children, replaced “your relative” with “your child” (Gallagher, Phillips, Oliver, & Carroll, 2008). The ZBI examines caregiving challenges in four subscales: burdens of the child’s dependence, burdens of exhaustion and uncertainty, burdens of guilt and fear for the child’s future, and burdens of consequences such as social and health burdens (Al-Rawashdeh, Lennie & Chung, 2016). The items are rated on a five-point scale range from 0 (never) to 4 (nearly always). The higher the scores, the higher the challenge. As suggested by the authors of the instrument, scores of 0–21 suggested little or no challenges, scores of 21–40 indicated mild to moderate challenges, scores of 41–60 indicated moderate to severe challenges and scores of 61–88 suggested severe challenges (Zarit et al., 1980). The ZBI has high internal consistency (Cronbach’s α at 0.88 and 0.91) and good test–retest reliability ($\alpha = 0.71$) (Gallagher, Rappaport, Benedict & Lovett, 1985; Hebert, Bravo & Preville, 2000).

3.3.7.2 Family crisis oriented personal evaluation scale

The parental coping strategies were measured by the 30-item F-COPES (see Appendix E) (McCubbin, Olson & Larsen, 1991). The F-COPES focuses on family interactions and family to environment interactions. Families with greater adaptation skills

at both levels will be more successful in coping with stress. Many F-COPES items are geared to the family's response to new problems. It is particularly useful for assessing families who care for individuals with disabilities because they reach new developmental milestones regularly, acquiring new behaviours or physical skills as they grow and develop or as the course of the disability changes (Padula, 1995).

The F-COPES contains five subscales. The acquiring social support subscale (nine items) measures a family's ability to acquire support from friends, relatives, neighbours and extended family. The reframing subscale (eight items) assesses the family's ability to redefine stressful events to help them be manageable by the family. The seeking spiritual support subscale (four items) examines the family's ability to acquire spiritual support. The mobilising family to acquire and accept help subscale (five items) measures the family's ability to seek community resources and accept help from others. The passive appraisal subscale (four items) assesses the family's ability to accept difficult issues, which minimises reactivity. The items are rated on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate a higher use of coping methods (McCubbin et al., 1991).

The cut-off points that were suggested by Chui and Chan (2007) are adopted in the current study. Scores < 50 indicated a low level of coping, scores of 51–99 indicated a moderate level of coping and scores > 100 indicated a high level of coping (Chui & Chan, 2007). Reliability (Cronbach's alpha) for the five subscales ranged from 0.63 to 0.83 and total scale alpha reliability was 0.86 (McCubbin et al., 1991).

F-COPES has been used in different populations, including parents with children who have learning disabilities, mental retardation or physical disabilities (Honey, Hastings & Mcconachie, 2005; Lustig, 2002; Moawad, 2012; Tway, Connolly & Novak, 2007). The psychometric characteristics of the F-COPES have been established in a group of 30

caregivers of individuals with a learning disability, with a Cronbach's alpha coefficient value of 0.84. The internal consistency on the subscales of F-COPES—reframing, acquiring social support, seeking spiritual support, passive appraisal and mobilising family to acquire and accept help—are also acceptable, with Cronbach's alpha values of 0.94, 0.89, 0.76, 0.82 and 0.85 respectively (Hassani, Abbasi, Zagheri Tafreshi, Zayeri & Ziapour, 2018).

3.3.7.3 Connor-Davidson resilience scale

The CD-RISC 10 (see Appendix F) (Connor & Davidson, 2003) was used to measure parental resilience. It is a self-rated unidimensional 10-item scale designed to measure resilience in different populations. CD-RISC 10 scores reflect the ability to bounce back from challenges that can arise in life. Items are rated on a five-point Likert scale from 0 (never) to 4 (almost always). The final score of the questionnaire is the sum of the responses obtained from each item (range 0–40). Higher scores indicate a higher level of resilience. The CD-RISC 10 has been used to examine resilience among caregivers of individuals with chronic diseases, such as children with a cancer diagnosis and patients with a mental disorder (Aloba et al., 2016; Ye et al., 2017). The Cronbach's alpha coefficient of CD-RISC 10 was 0.88 (Goins, Gregg & Fiske, 2013).

3.3.7.4 Sociodemographic data

The sociodemographic data (see Appendix G) of the participants were collected, including the parents' gender, age, nationality, ethnicity, religion, native language, education level, relationship with the child with disability, relationship or marital status, employment status, household income, number of children and immigration period, as well as the child with disability's diagnosis, gender and age. Data were also collected about the frequency and duration of any support that the parents received, such as from close family and/or friends, grandmothers, grandfathers, aunts, uncles and/or attending support services in the past or present.

3.3.8 Pilot testing

The study instruments were pilot tested in immigrant parents raising children with disabilities who were recruited from one NDIS centre in Newcastle (n = 15). Immigrant parents were asked to complete the study instruments and provide feedback. The pilot testing was conducted in Newcastle as it was a more feasible option than approaching the immigrant parents in Sydney. Immigrant parents in Newcastle were considered to have similar characteristics to those in Sydney.

The immigrant parents were approached by the researcher during one of the day activities held in the NDIS centre. The study instruments were distributed to immigrant parents with the study participant information sheet (PIS). A briefing was conducted by the researcher to ensure that the parents had an adequate understanding of the study. Immigrant parents were also invited to provide feedback on the instruments, including suggestions about how they could be improved. To give the participants adequate time to complete the questionnaire and provide feedback, they were allowed to take it home. Prepaid envelopes were provided by the researcher for the participants to return the questionnaire in. The immigrant parents were given three weeks to complete and return the questionnaires. The researcher provided her contact details in the PIS so that immigrant parents could contact her via email or phone.

The pilot test results found immigrant parents agreed that the questionnaires were comprehensive and acceptable. According to their feedback, the study instruments and sociodemographic sheet did not need any rewording or content amendments.

3.3.9 Data collection procedure

The recruitment took place over six months from September 2018 to February 2019. An organisational PIS (see Appendix H) and organisational consent form (see Appendix I) were sent to the NDIS study centres to obtain their approval. After receiving ethics

approval from the University of Newcastle (UON) and the seven NDIS centres, the researcher met with the case manager and/or coordinator of each of the seven centres to discuss the process of recruitment. The researcher answered queries raised by the case manager or coordinator. The researcher employed two recruitment strategies in this study:

1. The researcher obtained the schedule of the NDIS centres' regular activities, including their training sessions for children with disabilities and their families, from the venues' coordinators. Prior to the survey distribution date, posters explaining the study (see Appendix J) were placed in the study venues to encourage immigrant families to participate in the study. The researcher attended the regular centre activities to explain the study to potential participants. If potential participants were interested in the study, a caseworker at the centre who was not a member of the research team provided them with the PIS (see Appendix K). They were provided with opportunities to contact the researcher face to face or via phone to ask questions. The participants were given a maximum of two weeks to consider participating. After potential participants provided verbal consent to the researcher or the centre coordinator, the researcher and the coordinator checked their eligibility based on the inclusion/exclusion criteria. Eligible participants were provided with a package that contained a consent form (see Appendix L), a sociodemographic datasheet, three study instruments and a prepaid envelope. Eligible participants who decided to participate were briefed again by the researcher face to face in the centre about the aim of the study before they signed the written consent. In the consent form, the participants could choose to give consent for the survey only or for both phases—the survey and the interview. If the participants gave consent for both phases, they were required to provide their contact details to the

researcher. The participants had the choice to either fill in the questionnaire at a quiet place in the centre and return it to a locked box placed at the centre lobby, or fill in the questionnaire at home and return it to the university within two weeks using the prepaid envelope. The participants took about 30 minutes to complete the questionnaires. Participants who completed the survey received an A\$10 gift card as reimbursement for their transportation, as approved by the Human Research Ethics Committee (HREC) of the UON.

2. If there were two or more activity sessions held at the same time in different centres, the researcher asked the centre coordinator to promote the study at the site where the researcher could not attend. If parents were interested in the study and provided verbal consent, the centre coordinator would check their eligibility based on the inclusion/exclusion criteria. The centre coordinator distributed the package to the eligible participants. The participants signed the written consent and completed the questionnaire, then returned both to a locked box that was placed in the centre lobby by the researcher. The centre coordinators did not know who returned the survey or consented for the interview. Parents could also choose to complete the questionnaire at home and return it to the university within two weeks using a prepaid envelope. If the participants had questions or required any clarification about the study, they could contact the researcher via phone. Otherwise, the researcher arranged a time to meet the participants in the centre to answer their questions.

Different strategies were used to increase the response rate, such as word of mouth, posters and social media. Word of mouth has been considered the most effective strategy to improve recruitment, especially among participants from small groups (Greiner et al.,

2014). The current study also found word of mouth was the most effective recruitment strategy.

The researcher held meetings with immigrant parents during support groups or training sessions to promote the importance of the study and its expected outcomes. Posters were placed in the venues' halls to encourage participation. This helped target immigrant parents and raised their awareness of the study within the community. Social media platforms were utilised to promote the study. Facebook and WhatsApp applications, which were used by the NDIS teams to support immigrant families, were used to promote the study, as approved by the ethics committee of UON. Immigrant parents who were interested in the study were asked to contact the researcher to arrange a time and date to complete the questionnaire. Two weeks after the date of survey distribution, the researcher put up reminder posters in the venues' halls and sent messages using social media platforms to enhance the response rate.

The above recruitment strategies were considered effective. The researcher was able to recruit the required number of participants within six months.

3.3.10 Statistical analysis

SPSS Version 24 (IBM Corp, 2106) was used to analyse the data. Descriptive statistics were used to summarise the data, including frequencies, percentages, means and standard deviations (SD). This provided an overview of the challenges, coping strategies and levels of resilience experienced by the participants. Pearson correlation was used to examine the association among the ZBI, F-COPES and CD-RISC 10 results. T-tests and ANOVA were conducted for each of the three measures to explore potential differences in the challenges, coping strategies and levels of resilience among groups of different sociodemographic characteristics, including gender, age, marital status, socio-economic status, and ethnicity.

3.4 Phase Two: Qualitative Descriptive Study

3.4.1 Aim

The main aim of phase two was to understand the challenges, coping strategies, resilience, and barriers and facilitators of coping of immigrant parents raising children with disabilities from the perspectives of the parents and service providers.

3.4.2 Method

Semi-structured individual face-to-face interviews were used to collect data. They involved a series of open-ended questions, which were asked in a specific order to invite the participant to respond comprehensively (Polit & Beck, 2012). A semi-structured interview is useful as it allows the researcher flexibility to ask further questions to obtain the required details (Polit & Beck, 2012). This method enables the researcher to generate discussion and to further explore insights provided by the quantitative data, such as those related to perceived challenges, and to identify resilience and coping strategies used by immigrant parents. All the interviews were audio-recorded.

The interview guide for the parents and service providers was developed based on previous studies (Al-Azzam, 2011; Su, 2008). The drafted interview guide was consulted with five experts in this field, including three supervisors of the current study and two case managers/coordinators of NDIS. These experts had worked in the field of social work and healthcare for at least five years. The interview guide was revised based on the experts' comments.

The results of the first phase survey were used to refine the interview guide further. The following is the final interview guide for parents.

- What are the everyday challenges that you experience when raising a child with a disability in Australia? The follow-up questions are:

- Could you please tell me about your experience in providing care for a child with a disability?
- Could you please describe the impact of caring for a child with a disability on your life after immigration?
- Could you please tell me about your experience in raising a child with a disability in Australia which has a different language and culture from your homeland?
- What is the impact of living away from extended family? How does it impact your experience in raising your child with a disability in Australia?
- Could you please share your experience in utilising healthcare and educational systems in Australia?
- What made these challenges harder/easier?
- How do you cope to overcome your challenges? The possible follow-up questions are:
 - Can you please describe your usual response to the mentioned challenges?
 - What do you think that facilitate your coping?
 - What do you think that hinder your coping?
 - What kind of support services that are available in your area?

The following is the interview guide for service providers:

- Based on your experience, what are your perceived parental challenges of raising a child with a disability in Australia? The possible follow-up questions are:
 - Could you please describe your perception of parental everyday challenges in Australia?

- Could you please describe your experiences with immigrant parents in utilising services in Australia?
- What makes parents' challenges harder/easier?
- From your observation, how do immigrant parents cope to overcome their challenges? The possible follow-up questions are:
 - Can you describe your observation on a usual coping for those parents on their challenges?
 - What do you think that facilitate their coping?
 - What do you think that hinder their coping?

3.4.3 Interview technique

The researcher conducted all the interviews to maintain consistency. The interviews were audio-recorded to allow the researcher to concentrate on the discussion fully. Field notes were taken after the interview, including observations about non-verbal behaviour and ideas that arose from the interviews, to support the audio recordings. These notes were used during the data analysis process to support the findings and provide the researcher with the opportunity to reflect on what she experienced during the interview (Denzin & Lincoln, 2005).

The researcher followed the following list in conducting the study interviews:

- **Before the interview.** Participants were assured that their participation was voluntary and that they could skip any question they did not want to answer. Prior to commencing face-to-face or telephone interviews, the researcher explained to the participants the purpose of the interview again and provided an opportunity for them to ask questions. Demographic information was collected from parents and service providers prior to the interview.

- **At the beginning of the interview.** The researcher began the conversation in a polite manner and thanked the participant. The researcher then introduced herself and provided an overview of the study, including its purposes, the proposed use of the data and the topics to be discussed. The participants were encouraged to introduce themselves and provide simple background information, including their nationality, immigration period and data about their child's disability. Service provider participants were encouraged to introduce themselves and supply background information, including their work experience.
- **During the interview.** The interview was guided by the interview guide. The researcher ensured that each question she asked was understood, as confirmed by the participants, and allowed enough time for a well-generated response before moving on to another question. During the interviews, probing questions were asked as required to clarify what the participant had said—for example, 'can you please tell me more about that?' Rephrasing was used to clarify the meanings of questions and to capture the essence of what the participant was saying.
- **At the end of the interview.** To conclude the interview and confirm that all intended topics had been covered, the researcher asked the participants if they had anything else to add. The researcher thanked them for their participation. Immediately following the conclusion of the interview, the researcher recorded her field notes, including observations, methodological notes and personal notes.

3.4.4 Sampling

A purposive sampling approach was employed. A purposive sample is a type of non-probability sample that is selected based on the characteristics of a population and the objective of the study. Purposive sampling allows the researcher to focus on participants who will provide useful information to answer the research questions (Ross, 2012). This sampling method was chosen as the most appropriate method to address the research phenomena in the current study, as it is important for sequential design to use the same participants in both phases of the study. However, it is not necessary that the sample size of the two phases is equal. Usually, the sample size in qualitative studies is smaller than in quantitative studies (Creswell & Plano-Clark, 2007).

3.4.4.1 Parents sample

The inclusion and exclusion criteria of the parents' sample were similar to that of phase one. The sample was recruited purposively from the quantitative sample and included participants that could best provide the detail required to expand on the quantitative phase (Creswell & Plano-Clark, 2007). A purposive sample of immigrant parents with high, moderate and low levels of coping was recruited from those who consented for the interviews. This enriched the interviews with different perspectives and helped the researcher to understand different levels of parental coping. To create a balanced sample, an equal number of participants was recruited from each level of coping. A total of nine parents were recruited in this phase: three with a high level of coping, three with a moderate level of coping and three with a low level of coping.

3.4.4.2 Service providers sample

We sought the perspectives of NDIS service providers such as case managers and coordinators who were engaged in assessing, planning, implementing and evaluating services provided to immigrant families of children with disabilities. The inclusion criteria

were that the case manager or coordinator 1) had been working with NDIS for at least 12 months, which is a reasonable amount of time to obtain good experience in providing care to immigrant families, and 2) was willing to participate in the interview. Service providers who did not have face-to-face contact with immigrant parents were excluded.

The NDIS has 3,500 service providers in NSW, about 2,000 of whom work in Sydney and Newcastle. In the study venues, each centre had three to four case managers and coordinators that fitted the inclusion criteria. Nine case managers/coordinators were recruited from seven NDIS centres in this phase.

3.4.4.3 Sample size

The guiding principle for the sample size in the qualitative phase is data saturation. Data saturation refers to the continuation of data collection until the participants' descriptions no longer provide any new information and have become repetitive (Houser, 2011). The recruitment continued until data saturation was reached or when no new information was obtained by collecting further data. Data saturation was reached in the current study after nine participants in each group had been interviewed.

3.4.5 Data collection procedure

Following the completion of phase one, the data collection of the second phase started for both groups – parents and service providers. The second phase of the study took six months to complete (from March 2019 to August 2019). All interviews were digitally audio-recorded with the participants' consent.

3.4.5.1 Immigrant parents

A purposive sample was recruited that consisted of parents who consented to participate in the interview and had provided their contact details in the consent form. Forty-one immigrant parents provided consent to participate in the interview phase. The researcher contacted them via phone or email after analysing their level of coping. The

researcher explained the study to them again. An appointment was scheduled for an interview in one of the NDIS centres. The researcher started the interviews and continued until data saturation was achieved. The data reached saturation after the 9th interview of immigrant parents.

3.4.5.2 Service providers

Posters (see Appendix M) and PISs (see Appendix N) were placed by the researcher in the NDIS centres' offices to promote the study and to encourage service providers to participate. The poster and PIS contained researcher's email and phone number. Service providers who were interested in participating contacted the researcher. The researcher explained the study to the potential participants and answered their queries via email, over the phone or face to face. The eligibility of those who provided verbal consent was checked based on the inclusion/exclusion criteria. Sociodemographic data (see Appendix O) were collected over the phone. The researcher arranged appropriate dates and times with the eligible service providers to conduct the interviews in the NDIS centres. The researcher explained the study again before the interview and obtained written consent (see Appendix P). The data reached saturation after the 9th interview of the service providers. Seven face-to-face interviews were conducted in the NDIS centres and two interviews were conducted over the phone. All the interviews were conducted after the researcher received the signed consent from the service providers. All service providers were interviewed outside their work hours.

Immigrant parents and service providers received a A\$10 gift card as reimbursement for transportation when they completed the interview, as approved by the HREC at the UON.

3.4.6 Data analysis

All interviews were digitally audio-recorded and transcribed verbatim immediately after the interview. Content analysis was used to identify the themes from the data.

Qualitative content analysis is a dynamic data analysis process used widely in descriptive qualitative studies that aims at summarising the informational content of the data (Graneheim & Lundman, 2004). Data analysis and data collection were conducted simultaneously.

The entire transcript for each interview was divided into meaningful units and labelled with codes (Graneheim & Lundman, 2004). Meaningful units were defined by Graneheim and Lundman (2004) as ‘the constellation of words or statements that relate to the same central meaning’ (p. 106). In the current study, each response to the interview questions was considered a meaningful unit. The meaningful units were given descriptive codes. The assigned codes were based on broad topical areas consistent with the main aim of this study. The researcher then read within the coded data and created more discrete descriptive subthemes. The various subthemes were compared based on differences and similarities and sorted into themes (Sandelowski, 2000).

Once the transcripts had been analysed, the researcher created a report for each of the identified themes and subthemes. The report is a document listing each theme and subtheme and the corresponding quotes from the interviews that supported it. The researcher reviewed the data generated by the report to ensure that each quotation from the participants’ transcripts represented the theme and subtheme it was assigned to. The researcher also reviewed the transcripts and the field notes again to confirm that all essential codes had been captured. To validate the coding, the researcher and her supervisors met biweekly to review the transcripts and coding and to discuss data analysis. For an example of content analysis adopted in the current study, please see Appendix Q.

3.4.7 Trustworthiness of qualitative study

The principles of credibility, transferability, dependability, and confirmability are required to ensure trustworthiness in qualitative research, especially in descriptive qualitative studies using content analysis (Graneheim & Lundman, 2004; Sandelowski, 2000). These principles are parallel to measuring the validity, reliability and generalisability of quantitative studies.

3.4.8 Credibility

Credibility is the most important criterion for the assessment of qualitative research. It is similar to the concept of internal validity in quantitative research. Credibility refers to the believability of the findings (Anney, 2014). To establish this, the researcher used the following strategies:

- purposively selecting participants from the quantitative phase of the study who could provide rich data about the phenomena of interest, were from different cultural backgrounds, displayed different coping levels and who were mothers and fathers;
- deciding the amount of data that was necessary to answer the questions of the study based on data saturation;
- selecting the appropriate, meaningful units during data analysis;
- identifying the similarities and differences between themes;
- ensuring the accuracy of the codes, themes, data analysis and study findings via regular meetings with the researcher's supervisors to discuss the data analysis and the study; and
- ensuring objectivity in the research process by bracketing preconceived notions about the study topic. The researcher reflected and discussed personal biases,

experience and knowledge about the current topic with her supervisors throughout the research process.

3.4.9 Transferability

Transferability means the degree to which the findings and outcomes can be applied or generalised to other contexts, settings or groups (Lincoln & Guba, 1985). Transferability is similar to generalisability in quantitative research. To achieve this, a clear description of the participants was provided in the current report that included the participants' background, cultural characteristics and religion. The participants' selection criteria and characteristics were clearly described. Detailed descriptions of the processes of data collection and analysis provided in the study report enable readers to judge the transferability of the study findings to other settings. Using appropriate participants' quotations to justify subthemes was also a strategy to gain transferability.

3.4.10 Dependability

Dependability refers to the researcher's precautions throughout the research process to protect against changes in data over time and to document any changes in the researcher's decisions while collecting and analysing data (Lincoln & Guba, 1985). To establish the dependability of the current study, specific procedures were implemented. The use of an interview guide ensured that questions were asked consistently across participants and that all the study dimensions were covered during each interview with each participant. Regular meetings were scheduled between the researcher and her supervisors to discuss, evaluate and document the steps taken during sampling, data collection, analysis (including the coding process) and writing of the study report. Field notes were used to document the researcher's experiences and observations after each interview. For example, one of the participants was a mother of a five-year-old boy with autism and, during the interview, the researcher noted that the mother sent mixed messages through her conversational and body

language (looked anxious but stated that she was relaxed and fine) ...”she was embarrassed of her English language skills, could that explain her mixed messages”.

3.4.11 Confirmability

Confirmability refers to the extent to which the findings are realistic, reflect the actual responses of the participants and are free of any bias or motivation from the researcher (Lincoln & Guba, 1985). To demonstrate confirmability, the research process was clearly documented for checking and rechecking by the supervisors throughout the study. One of the researcher’s supervisors was involved to confirm the accuracy and relevance of the primary data.

3.5 Ethical Consideration

This research project was conducted in accordance with the ethical standards established by the Australian Research Council and the National Health and Medical Research (National Health and Medical Research Council, 2015).

3.6 Ethical Approvals

Prior to implementing this study, ethical approval from the HREC at the UON was sought (H-2018-0283) (see Appendix R). Prior to the data collection process, an organisational PIS and consent form were sent to the study venues and were signed by case managers and coordinators to obtain their consent on behalf of the organisation.

3.7 Informed Consent

Prior to involving participants in the research, both verbal and written information was provided to them to ensure that they were fully aware of this study and its nature. The PIS (see Appendix K) included the purpose of the study, the requirements of participation, the benefits, the risks and the participants’ rights, as well as the researcher’s contact details for further queries. All participants signed the informed consent (see Appendix L). The

researcher informed the participants that they could obtain a copy of the summary of results by sending an email to the chief investigator after 30 December 2019. She would send them a summary of the research findings within two weeks. The researcher did not receive any request from parents or service providers in regards to the study results to date.

The participants were assured that the service they received from the study venue would not be affected by whether they participated in the study. Further, the participants (parents and service providers) were informed that their participation was completely voluntary, both verbally by the researcher and in writing in the PIS and that they had the right to withdraw from the study at any time without having to give a reason and without any negative consequences for themselves or their children. They were also assured that they could refuse to answer any question and that they could stop the interview if they felt that they could not proceed with the process.

3.8 Beneficence and Non-maleficence

In research ethics, the researcher is responsible for protecting the participants from any physical, emotional or social harm that might result from the research and anticipating any potential adverse consequences. The principles of beneficence and non-maleficence involve maximising the benefits and minimising the risk in a research study (Avasthi, Ghosh, Sarkar & Grover, 2013).

To ensure that this was achieved, the researcher provided information to participants about the resources available to support them. All participants were informed that the survey and interview questions involved their caregiving experience of their child with a disability. If participants were upset or distressed while completing the survey or during the interview, the researcher would stop the survey or interview, and give the participants a chance to decide whether they wanted to skip any question, withdraw from the study,

reschedule or carry on. The researcher would report to the centre's case manager in charge immediately if participants became distressed while completing the questionnaire or during an interview. The centre's case manager provided information on the counselling services available if the participants required it. However, in the present study, no participant needed to stop, required a report to a case manager or needed to contact lifeline.

3.9 Anonymity, Privacy and Confidentiality

The anonymity, privacy and confidentiality of the research participants were always respected and protected, both during and after the course of the research. Surveys did not contain the participants' names; only code was used. Pseudonyms were used in the interview transcripts. The participants' identities will not be revealed in the study reports or publications. All collected data are kept strictly confidential and will not be accessed by anyone except the researcher and her supervisors.

3.10 Storage of Information

Data will be retained for at least five years on the UON's ownCloud secure server and can be accessed only by the researcher and study supervisors. Hard copies of the surveys were stored in a locked filing cabinet in the chief investigator's office. Audio recordings were stored on the UON's ownCloud secure server, which is password protected. Data will be destroyed after a maximum of five years, which is in line with UON's policy provisions for research conducted by university staff. If participants decide to withdraw, all the information relating to them will be destroyed. However, no participant has requested to withdraw from the study.

3.11 Summary

This chapter discussed the methodology and methods of the present study. The study adopted a sequential explanatory design with a quantitative survey in the first phase

and a qualitative interview in the second phase. In the first phase, 134 immigrant parents of children with disabilities completed the quantitative survey. The data generated from the survey guided the purposive sampling of the second phase, which was an individual semi-structured interview. Nine immigrant parents and nine service providers were interviewed. The results of both phases were integrated into the interpretation phase. The next chapter will present the results of the first phase: the quantitative survey.

Chapter 4: Phase One Results

4.1 Introduction

This chapter discusses the results of the phase one study – the questionnaire survey. Descriptive statistics will be reported, including frequencies, percentages, means and SD for the items of each of the three measures. The relationship between the main measures and pairwise correlations between the ZBI, F-COPES and CD-RISC 10 will be presented.

4.2 Response Rate

Out of the 237 immigrant parents approached by the researcher, 134 completed and returned the survey within the data collection period. The total response rate in Sydney it was 47.01% and was 52.98% in Newcastle. Table 4 shows the total number of immigrant parents approached by the researcher in both cities (Sydney and Newcastle) and the response rate of each city, which was very similar.

Table 4

Response Rate of Immigrant Parents in Each Region (n = 134)

Study region	Number of parents approached by the researcher	Number of parents completed survey	Response rate (%)
Sydney	110	63	47.01
Newcastle	127	71	52.98

4.3 Sample Characteristics

Table 5 shows the sociodemographic characteristics of participants. A large majority of them were mothers (n = 84, 62.7%), aged between 31–40 years (n = 64, 47.8%), who were from an Arabic background (n = 73, 54.5%), spoke Arabic language (n = 77, 57.5%) and had university or higher education level (n = 43, 32.1%). Islam was the most common religion among participants (n = 72, 53.7%). Most participants were married

(n = 111, 82.8%), employed (n = 66, 49.3%) and earned between A\$5000–10 000 per month (n = 83, 61.9%). Fifty-seven of the participants (42.5%) migrated to Australia for 6–10 years. About half of the immigrant parents had 1–3 children (n = 69, 51.5%). Eighty participants (59.7%) reported that they did not have close family support. Most participants attended support services for their child with a disability (n = 121, 90.3%). There are three missing values in Table 5 and Table 6 because three participants did not complete the sociodemographic part of the survey.

Table 6 shows the characteristics of the children with disabilities in the current study. The majority of the children with disabilities were female (n = 69, 51.5%), aged 6–10 years old (n = 49, 36.6%) and diagnosed with a physical disability (n = 48, 35.8%).

Table 5

Sociodemographic Characteristics (n = 134)

Characteristic	N	%
Gender		
Mother	84	62.7
Father	50	37.3
Age		
20–30	18	13.4
31–40	64	47.8
41–50	36	26.9
> 51	13	9.7
Missing	3	2.2
Nationality		
Arabic	73	54.5
Indian	15	11.2
Afghani	14	10.4
Italian	8	6.0
Other	21	15.7
Missing	3	2.2
Language		
Arabic	77	57.5
Italian	8	6.0
Dari	12	9.0
Hindi	14	10.4
Other	20	14.9
Missing	3	2.2
Education		
University or higher	43	32.1
College	29	21.6
High school	28	20.9
Primary school	14	10.4
No education	17	12.8
Missing	3	2.2
Religion		
Christian	38	28.4
Muslim	72	53.7
Hindu	6	4.5
No religion	8	6.0
Other	7	5.2
Missing	3	2.2

Characteristic	N	%
Marital status		
Single	7	5.2
Married	111	82.8
Divorced	12	9.0
Other	1	0.8
Missing	3	2.2
Employment		
Employed	66	49.3
Unemployed	61	45.5
Retired	4	3.0
Missing	3	2.2
Number of children		
1–3	69	51.5
4–6	54	40.3
> 6	8	6.0
Missing	3	2.2
Household income per month		
Low (< A\$5000)	27	20.2
Moderate (A\$5000–10 000)	83	61.9
High (> A\$10 000)	21	15.7
Missing	3	2.2
Immigration period		
0–5 years	38	28.4
6–10 years	57	42.5
> 10 years	36	26.9
Missing	3	2.2
Close family support		
Yes	54	40.3
No	80	59.7
Attend support services		
Yes	128	95.5
No	0	0.0
Missing	6	4.5

Table 6

Characteristics of Immigrants' Children with Disability (n = 134)

Characteristic	N	%
Child's diagnosis		
Autism	45	33.6
Cerebral palsy	19	14.2
Physical disability	48	35.8
Mental illness	22	16.4
Child's gender		
Male	62	46.3
Female	69	51.5
Missing	3	2.2
Child's age		
0–5 years	44	32.8
6–10 years	49	36.6
11–15 years	27	20.1
16–18 years	14	10.5

4.4 Challenges, Coping and Resilience of Immigrant Parents

Table 7 shows the range and mean (SD) of the challenges, coping and resilience questionnaires scores. There was no significant difference in challenges, coping and resilience levels between the immigrant parents in the two cities: Newcastle and Sydney.

Table 7

Differences between Newcastle and Sydney Participants in Challenges, Coping and Resilience

Measures	Newcastle (n = 71) Mean (SD)	Sydney (n = 63) Mean (SD)	T	P
ZBI: Total	45.96(19.63)	46.38(19.93)	1.221	.230
ZBI: Burden consequences	21.24(9.09)	22.44(9.78)	1.280	.188
ZBI: Burden child's dependence	6.68(2.70)	7.30(3.07)	1.410	.161
ZBI: Burden exhaustion and uncertainty	8.68(4.31)	9.00(4.26)	0.544	.617
ZBI: Burden guilt and fear for child's future	5.68(2.23)	6.37(3.22)	1.311	.188
F-COPES: Total	92.34(31.04)	90.55(30.73)	0.702	.460
F-COPES: Acquiring social support	25.98(9.78)	25.02(8.75)	0.511	.563
F-COPES: Seeking spiritual coping	12.74(4.30)	11.31(4.05)	0.532	.588
F-COPES: Mobilising family to acquire & accept help	12.46(4.18)	11.99(4.78)	1.316	.353
F-COPES: Passive appraisal	10.44(4.67)	10.33(3.71)	0.177	.890
F-COPES: Reframing	23.08(8.40)	24.13(8.76)	0.392	.600
CD-RISC 10	25.01(9.35)	25.87(10.32)	0.302	.633

ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

4.4.1 Challenges

The ZBI was used to measure the challenges faced by immigrant parents of children with disabilities, including their burdens. Thirty-six participants (26.9%) experienced a severe level of challenges, scoring 61–88 on the ZBI; 39 (29.1%) experienced a moderate to high level of challenges, scoring 41–60 on the ZBI; 49 (36.5%) experienced a mild to moderate level of challenges, scoring 21–40 on the ZBI; and 10 (7.5%) experienced a low level of challenges, scoring < 21 on the ZBI (see Table 8).

Table 8

Levels of Challenges on the ZBI

Level of ZBI (score range)	N	%
Severe level of challenges (61–88)	36	26.9
Moderate to high level of challenges (41–60)	39	29.1
Mild to moderate level of challenges (21–40)	49	36.5
Low level of challenges (< 21)	10	7.5

ZBI = Zarit burden interview scale.

The mean total score on the ZBI was 45.73 (SD = 20.14), which suggested that parents experienced a moderate level of challenges. The highest perceived challenge was in the ‘caring consequences’ subscale (mean = 21.62, SD = 9.55), followed by the ‘burden of exhaustion and uncertainty’ subscale (mean = 8.95, SD = 4.62), ‘burden of child’s dependence’ subscale (mean = 7.11, SD = 3.01), and ‘burden of guilt and fear for child’s future’ subscale (mean = 6.11, SD = 2.97) (see Table 9).

Table 9

Summary Scores of ZBI (n = 134)

ZBI subscale	Possible range	Actual range	Mean (SD)	Rank
Total	0–88	13–88	45.73(20.14)	–
Burden of caring consequences	0–40	2–40	21.62(9.55)	1
Burden of exhaustion and uncertainty	0–20	0–20	8.95(4.62)	2
Burden of child’s dependence	0–12	1–12	7.11(3.01)	3
Burden of guilt and fear for child’s future	0–12	1–12	6.11(2.97)	4

ZBI = Zarit burden interview scale.

In the ‘burden of caring consequences’ subscale, the item ‘feeling stressed between caring for the child with a disability and trying to meet other responsibilities for family or work’ (mean = 3.7, SD = 0.6) had the highest scores. The items ‘do you feel that you don’t have enough money to take care of your child in addition to the rest of your expenses?’ (mean = 2.3, SD = 0.6) and ‘do you feel angry when you are around your child?’

(mean = 2.3, SD = 0.6) had the lowest scores. Table 10 shows the item scores of the ‘burden of consequences of caregiving’ subscale in rank order.

Table 10

Consequences of Caregiving Subscale (n = 134)

Rank	Question	Mean	SD
1	Q3: Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?	3.8	0.6
2	Q2: Do you feel that because of the time you spend with your child that you don’t have enough time for yourself?	3.5	0.5
3	Q12: Do you feel that your social life has suffered because you are caring for your child?	3.3	0.7
4	Q9: Do you feel strained when you are around your child?	3.2	0.7
5	Q6: Do you feel that your child currently affects your relationships with other family members or friends in a negative way?	3.0	0.5
5	Q11: Do you feel that you don’t have as much privacy as you would like because of your child?	3.0	0.5
6	Q17: Do you feel you have lost control of your life since your child’s illness?	2.6	0.5
7	Q10: Do you feel your health has suffered because of your involvement with your child?	2.5	0.6
8	Q5: Do you feel angry when you are around your child?	2.3	0.7
8	Q15: Do you feel that you don’t have enough money to take care of your child in addition to the rest of your expenses?	2.3	0.6

The ‘exhaustion and uncertainty’ subscale had the second-highest scores among the four subscales (mean = 8.95, SD = 4.62). The item ‘feeling embarrassed over your child’s behaviour’ had the highest rating in this subscale (mean = 3.7, SD = 0.5). The item ‘wish not to leave the care of their child to anyone else’ had the lowest scores in this subscale (mean = 1.1, SD = 0.4). Table 11 shows the item ratings for the ‘exhaustion and uncertainty’ subscale in rank order.

Table 11

Exhaustion and Uncertainty Subscale (n = 134)

Rank	Question	Mean	SD
1	Q4: Do you feel embarrassed over your child's behaviour?	3.7	0.5
2	Q13: Do you feel uncomfortable about having friends over because of your child?	3.6	0.6
3	Q19: Do you feel uncertain about what to do about your child?	3.2	0.5
4	Q16: Do you feel that you will be unable to take care of your child much longer?	2.1	0.4
5	Q18: Do you wish you could leave the care of your child to someone else?	1.1	0.4

In the 'burden of child's dependence' subscale, the item that had the highest scores was 'feel that the child with a disability is dependent on them' (mean = 2.8, SD = 0.5). The lowest scoring item was 'do you feel that your child asks for more help than he/she needs?' (mean = 2.2, SD = 0.4). Table 12 presents the items of the 'burden of child's dependence' subscale in rank order.

Table 12

Child's Dependence Subscale (n = 134)

Rank	Question	Mean	SD
1	Q8: Do you feel your child is dependent on you?	2.8	0.5
2	Q14: Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?	2.5	0.4
3	Q1: Do you feel that your child asks for more help than he/she needs?	2.2	0.4

In the 'guilt and fear for child's future' subscale, the item 'feeling afraid about what the future holds' had the highest scores (mean = 1.6, SD = 0.5) and the item 'do you feel you should be doing more for your child?' had the lowest scores (mean = 1.1, SD = 0.5). Table 13 shows the items of the 'guilt and fear of child's future' subscale in rank order.

Table 13

Guilt and Fear of Child's Future Subscale (n = 134)

Rank	Question	Mean	SD
1	Q7: Are you afraid what the future holds for your child?	1.6	0.5
2	Q21: Do you feel you could do a better job in caring for your child?	1.3	0.5
3	Q20: Do you feel you should be doing more for your child?	1.1	0.5

4.4.2 Coping

The F-COPES was used to measure coping strategies used by the parents. The mean total score of F-COPES was 90.08, (SD = 31.42), which was considered a moderate level of coping. The immigrant parents adopted 'reframing' as the most common coping strategy (mean = 24.41, SD = 8.67), followed by 'mobilising family to acquire and accept help' (mean = 16.50, SD = 6.05) and 'passive appraisal' (mean = 11.37, SD = 4.68) (see Table 14).

Table 14

Summary Scores of F-COPES (n = 134)

Rank	F-COPES subscale	Possible range	Actual range	Mean (SD)
–	Total	30–150	30–150	90.08(31.42)
1	Reframing	8–40	8–40	24.41(8.67)
2	Mobilising family to acquire & accept help	4–20	13–20	16.50(6.05)
3	Seeking spiritual coping	4–20	11–20	15.47(5.85)
4	Acquiring social support	9–45	9–20	14.38(5.47)
5	Passive appraisal	4–20	4–20	11.37(4.68)

F-COPES = family crisis oriented personal evaluation scale.

In the 'reframing' subscale, the item 'believing we can handle our own problems' (mean = 4.7, SD = 0.4) had the highest scores, indicating that the participants utilised this coping strategy most often. The item that had the lowest scores in this subscale was 'accepting that difficulties occur unexpectedly' (mean = 3.9, SD = 0.6) (see Table 15).

Table 15

Reframing Coping Subscale (n = 134)

Rank	Item	Mean	SD
1	Q22: Believing we can handle our own problems	4.7	0.4
2	Q11: Facing the problems ‘head on’ and trying to get solutions right away	4.5	0.6
2	Q24: Defining the family problems in a more positive way so that we do not become too discouraged	4.5	0.4
3	Q3: Knowing we have the power to solve major problems	4.3	0.5
3	Q13: Showing that we are strong	4.3	0.5
4	Q7: Knowing that we have the strength within our own family to solve our problems	4.2	0.4
5	Q18: Exercising with friends to stay fit and reduce tension	4.1	0.5
6	Q19: Accepting that difficulties occur unexpectedly	3.9	0.6

‘Mobilising family to acquire and accept help’ (mean = 16.50, SD = 6.05) was the second highest rated subscale. The highest rating item in this subscale was ‘seeking professional counselling and help for family difficulties’ (mean = 4.6, SD = 0.5) and the lowest rating item was ‘seeking information and advice from persons in other families who have faced the same or similar problems’ (mean = 4.0, SD = 0.5) (see Table 16).

Table 16

Accepting Help from Others Subscale (n = 134)

Rank	Item	Mean	SD
1	Q21: Seeking professional counselling and help for family difficulties	4.6	0.5
2	Q6: Seeking assistance from community agencies and programs designed to help families in our situation	4.3	0.5
2	Q9: Seeking information and advice from the family doctor	4.3	0.5
3	Q4: Seeking information and advice from persons in other families who have faced the same or similar problems	4.0	0.5

Seeking spiritual coping (mean = 15.47, SD = 5.85) was the third highest rated strategy utilised by the participants. ‘Having faith in God’ was the highest-rated item in this subscale (mean = 3.7, SD = 0.5), followed by ‘participating in church activities’ (mean = 3.5, SD = 0.6). The lowest rated item in this subscale was ‘attending church activities’ (mean = 3.0, SD = 0.6) (see Table 17).

Table 17

Seeking Spiritual Support Subscale (n = 134)

Rank	Item	Mean	SD
1	Q30: Having faith in God	3.7	0.5
2	Q23: Participating in church activities	3.5	0.6
3	Q27: Seeking advice from a minister	3.2	0.4
4	Q14: Attending church services	3.0	0.6

In the ‘acquiring social support’ subscale (mean = 14.38, SD = 5.47), the item ‘sharing concerns with close friends’ had the highest scores (mean = 2.8, SD = 0.5). The lowest rating item was ‘sharing problems with neighbours’ (mean = 1.7, SD = 0.5) (see Table 18).

Table 18

Acquiring Social Support Subscale (n = 134)

Rank	Item	Mean	SD
1	Q16: Sharing concerns with close friends	2.8	0.5
2	Q1: Sharing our difficulties with relatives	2.6	0.5
2	Q20: Doing things with relatives (get togethers, dinners, etc.)	2.6	0.7
3	Q2: Seeking encouragement and support from friends	2.5	0.4
4	Q5: Seeking advice from relatives (grandparents, etc.)	2.4	0.4
5	Q25: Asking relatives how they feel about problems we face	2.1	0.4
6	Q10: Asking neighbours for favours and assistance	2.0	0.5
7	Q8: Receiving gifts and favours from neighbours	1.9	0.4
8	Q29: Sharing problems with neighbours	1.7	0.5

The least used coping strategy in the current study was ‘passive appraisal’ (mean = 11.37, SD = 4.68). Table 19 shows that the highest passive appraisal coping utilised by immigrant parents was ‘watching TV’ (mean = 1.9, SD = 0.4) and ‘knowing luck plays a big part in how well we are able to solve family problems’ (mean = 1.9, SD = 0.5). The lowest scoring item in this subscale was ‘believing if we wait long enough, the problem will go away’ (mean = 1.2, SD = 0.4).

Table 19

Passive Appraisal Subscale (n = 134)

Rank	Item	Mean	SD
1	Q12: Watching television	1.9	0.4
1	Q17: Knowing luck plays a big part in how well we are able to solve family problems	1.9	0.5
2	Q26: Feeling that no matter what we do to prepare, we will have difficulty handling problems	1.5	0.5
3	Q28: Believing if we wait long enough, the problem will go away	1.2	0.4

4.4.3 Resilience

The CD-RISC 10 measured participants’ resilience. The CD-RISC 10 scores range was 4–40. The mean score of CD-RISC 10 was 26.12 (SD = 10.94), which was considered moderate. Table 20 presents the rating of all the items in CD-RISC 10. ‘Adapt to change’

was the highest rating item (mean = 3.4, SD = 0.5). The lowest rating item was ‘can handle unpleasant feelings’ (mean = 2.2, SD = 0.7).

Table 20

CD-RISC 10 Mean Scores

Rank	Item	Mean	SD
1	1. Adapt to change	3.4	0.5
2	8. Not easily discouraged by failure	3.2	0.5
3	2. Can deal with whatever comes	3.1	0.7
3	7. Can stay focused under pressure	3.1	0.5
3	5. Tends to bounce back after illness or hardship	3.1	0.6
4	9. Thinks of self as a strong person	3.0	0.7
5	3. Tries to see humorous side of problems	2.9	0.3
5	4. Coping with stress can strengthen me	2.9	0.5
6	6. Can achieve goals despite obstacles	2.5	0.6
7	10. Can handle unpleasant feelings	2.2	0.6

CD-RISC 10 = Conner-Davidson resilience scale

4.5 Relationship between Challenges, Coping and Resilience

Table 21 presents the correlation among the ZBI, F-COPES and CD-RISC 10 scores. The ZBI total scores had a strong negative correlation with the F-COPES total scores ($r = -.796$, $p = .5$) and all its subscale scores. All ZBI subscales had a strong negative correlation with the F-COPES subscales. That means immigrant parents who had higher challenges scores had lower coping scores.

When examining the coping subscales and ZBI total scores, the results showed that immigrant parents who had higher scores in ‘reframing’ ($r = -.795$, $p = .05$) ‘sought spiritual support’ ($r = -.759$, $p = .05$) and ‘mobilising family to acquire and accept help’ ($r = -.750$, $p = .05$) had lower ZBI scores. That means those who had higher challenges scores used less reframing, seeking spiritual support and mobilising family to acquire and accept help coping strategies.

The CD-RISC 10 total scores had a strong positive correlation with the F-COPES scores ($r = .855$, $p = .05$) and all its subscales, indicating that immigrant parents who had high resilience scores used more coping strategies. Results also indicated that those who used more reframing coping strategies had higher CD-RISC 10 scores ($r = .849$, $p = .01$). CD-RISC 10 had a strong negative correlation with the ZBI total ($r = -.800$, $p = .05$) and all its subscales, indicating that immigrant parents who had high resilience scores had lower-level challenges.

Table 21

Correlation between Study Variables (n = 134)

Measures	1	2	3	4	5	6	7	8	9	10	11	12
ZBI: Total	1											
ZBI: Burden of caring consequences	.832	1										
ZBI: Burden of child's dependence	.765	.855	1									
ZBI: Burden of exhaustion and uncertainty	.799	.798	.810	1								
ZBI: Burden of guilt and fear for child's future	.766	.821	.764	.816	1							
F-COPES: Total	-.796*	-.778*	-.766*	-.696*	-.706*	1						
F-COPES: Acquiring social support	-.712*	-.741**	-.756*	-.615**	-.676*	.812	1					
F-COPES: Seeking spiritual coping	-.759*	-.744*	-.703*	-.712*	-.663**	.871	.794	1				
F-COPES: Mobilising family to acquire & accept help	-.750*	-.724*	-.602*	-.665*	-.681*	.799	.801	.799	1			
F-COPES: Passive appraisal	-.677*	-.631**	-.719*	-.534*	-.612*	.877	.765	.811	.800	1		
F-COPES: Reframing	-.795*	-.793*	-.710*	-.745*	-.699*	.756	.781	.845	.734	.789	1	
CD-RISC 10	-.800*	-.788*	-.773*	-.692*	-.756*	.855*	.812*	.827*	.742*	.794*	.849**	1

*Correlation is significant at the 0.05 (two-tailed); **Correlation is significant at the 0.01 level (two-tailed); ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

4.6 Challenges, Coping and Resilience among Groups of Different Sociodemographic Characteristics

There was no significant difference found between mothers and fathers in all study variables: challenges, coping and resilience scores (see Table 22).

Table 22

Differences between Mothers and Fathers in Challenges, Coping and Resilience Scores

Measures	Fathers (n = 50) Mean (SD)	Mothers (n = 84) Mean (SD)	T	P
ZBI: Total	42.96(18.63)	47.38(20.93)	1.231	.220
ZBI: Burden of consequences	20.24(9.09)	22.44(9.78)	1.293	.198
ZBI: Burden of child's dependence	6.64(2.70)	7.40(3.17)	1.410	.161
ZBI: Burden of exhaustion and uncertainty	8.68(4.41)	9.11(4.76)	0.516	.607
ZBI: Burden of guilt and fear for child's future	5.68(2.63)	6.37(3.14)	1.302	.195
F-COPES: Total	92.66(31.04)	88.55(31.73)	0.732	.466
F-COPES: Acquiring social support	26.98(9.98)	26.02(9.75)	0.554	.587
F-COPES: Seeking spiritual coping	12.74(4.30)	12.31(4.55)	0.541	.590
F-COPES: Mobilising family to acquire & accept help	13.46(4.38)	12.62(4.78)	1.016	.311
F-COPES: Passive appraisal	11.44(4.67)	11.33(4.71)	0.127	.899
F-COPES: Reframing	24.88(8.400)	24.13(8.87)	0.482	.630
CD-RISC 10	26.54(10.35)	25.87(11.32)	0.342	.733

ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

There was no significant difference in challenges, coping and resilience scores between immigrant parents who had a male or female child with a disability (see Table 23).

Table 23

Differences in Challenges, Coping and Resilience Scores between Immigrant Parents based on Child's Gender

Measures	Parents had male child (n = 62)	Parents had female child (n = 69)	T	P
	Mean (SD)	Mean (SD)		
ZBI: Total	48.71(19.17)	43.38(20.03)	1.331	.132
ZBI: Burden of consequences	22.24(9.29)	23.04(8.78)	1.353	.098
ZBI: Burden of child's dependence	6.84(2.80)	6.90(3.77)	1.330	.301
ZBI: Burden of exhaustion and uncertainty	8.72(4.62)	9.23(4.83)	0.626	.407
ZBI: Burden of guilt and fear for child's future	4.98(2.73)	7.37(2.99)	1.882	.096
F-COPES: Total	86.66(29.04)	93.55(32.73)	0.532	.646
F-COPES: Acquiring social support	24.98(9.08)	27.12(9.45)	0.504	.447
F-COPES: Seeking spiritual coping	11.74(4.10)	11.30(4.65)	0.741	.190
F-COPES: Mobilising family to acquire & accept help	12.66(4.00)	13.03(4.00)	1.226	.261
F-COPES: Passive appraisal	12.01(3.99)	12.21(4.31)	0.207	.739
F-COPES: Reframing	26.11(9.100)	23.99(7.87)	0.462	.631
CD-RISC 10	25.54(10.15)	27.87(11.02)	0.300	.533

ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale;
CD-RISC 10 = Connor-Davidson resilience scale.

There was no significant difference in challenges, coping and resilience between immigrant parents who had close family living in Australia and those who did not (see Table 24).

Table 24

Differences between Immigrant Parents Who Had Close Family Living in Australia and Those Who Did Not in Challenges, Coping and Resilience

Measures	Parents had family support (n = 20) Mean (SD)	Parents had no family support (n = 80) Mean (SD)	T	P
ZBI: Total	39.76(17.52)	47.38(24.90)	1.201	.120
ZBI: Burden of consequences	22.24(8.69)	23.14(9.48)	1.093	.158
ZBI: Burden of child's dependence	8.60(2.40)	7.70(2.17)	1.710	.131
ZBI: Burden of exhaustion and uncertainty	8.37(4.33)	8.01(3.86)	0.536	.507
ZBI: Burden of guilt and fear for child's future	4.98(3.63)	5.37(2.24)	1.322	.095
F-COPES: Total	93.55(33.04)	85.55(34.03)	0.931	.476
F-COPES: Acquiring social support	28.98(8.78)	24.02(7.05)	0.534	.387
F-COPES: Seeking spiritual coping	13.78(4.55)	14.31(3.51)	0.577	.540
F-COPES: Mobilising family to acquire & accept help	14.46(6.38)	11.62(5.78)	1.326	.911
F-COPES: Passive appraisal	13.04(4.67)	13.33(4.91)	0.167	.699
F-COPES: Reframing	24.88(8.400)	25.13(7.81)	0.452	.611
CD-RISC 10	27.54(11.35)	23.87(12.32)	0.442	.781

ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

The findings showed no significant difference in immigrant parents' challenges ($F = 1.032$; d.f = 3, 127; $p = .381$), coping ($F = 2.254$; d.f = 3, 127; $p = .098$) and resilience ($F = 2.320$; d.f = 3, 127; $p = .791$) among different age groups. There was no significant difference among groups with a different nationality at birth in their challenges ($F = 1.874$; d.f = 3, 127; $p = .092$), coping ($F = 2.254$; d.f = 3, 127; $p = .321$) and resilience ($F = 2.320$; d.f = 3, 127; $p = .234$) scores. Also, there was no significant difference in immigrant parents' challenges ($F = 2.874$; d.f = 4, 126; $p = .080$), coping ($F = 2.364$; d.f = 4, 126; $p = .125$) and resilience ($F = 2.320$; d.f = 4, 126; $p = .141$) among parents who spoke different languages.

When examining the differences between immigrant parents' challenges, coping and resilience among different religions, the findings showed that there were significant differences in immigrant parents' challenges ($F = 2.626$; $d.f = 4, 126$; $p = .038$), but not in coping ($F = 2.393$; $d.f = 3, 126$; $p = .059$) or resilience ($F = 1.820$; $d.f = 3, 126$; $p = .129$) scores. Muslim immigrant parents had the lowest challenges when compared with the other groups (Hindu, Christian, no religion and other) in the overall ZBI scores and all ZBI subscales scores 'burden consequences' ($F = 3.128$; $d.f = 4, 126$; $p = .017$), 'burden of child's dependence' ($F = 2.407$; $d.f = 4, 126$; $p = .050$), 'burden of exhaustion and uncertainty' ($F = 1.620$; $d.f = 4, 126$; $p = .029$) and 'burden of guilt and fear for child's future' ($F = 2.743$; $d.f = 4, 126$; $p = .031$) (see Table 25).

Table 25

Challenges by Different Religion Group

Item	Religion	Mean	SD	F	95% CI	
ZBI score	Christian	50.47	18.478	2.626*	44.40	−56.55
	Muslim	43.29	19.845		38.63	−47.95
	Hindu	63.33	15.069		47.52	−79.15
	No religion	55.50	20.591		48.29	−60.71
	Other	44.29	23.049		22.97	−65.60
Burden consequences	Christian	24.34	8.948	3.128*	21.40	−27.28
	Muslim	20.24	9.453		18.01	−22.46
	Hindu	30.00	6.099		23.60	−36.40
	No religion	36.50	8.832		29.12	−43.88
	Other	21.00	9.661		12.07	−29.93
Burden of child's dependence	Christian	7.71	2.977	2.407*	6.73	−8.69
	Muslim	6.92	2.960		6.21	−7.62
	Hindu	9.50	1.643		7.78	−11.22
	No religion	9.25	2.765		7.94	−11.56
	Other	6.43	2.878		3.77	−9.09
Burden of exhaustion and uncertainty	Christian	9.39	4.636	1.620*	7.87	−10.92
	Muslim	8.50	4.370		7.47	−9.53
	Hindu	12.83	4.708		7.89	−17.77
	No religion	11.50	5.071		8.26	−15.74
	Other	9.86	5.551		4.72	−14.99
Burden of guilt and fear for child's future	Christian	6.97	2.982	2.743*	5.99	−7.95
	Muslim	5.69	2.781		5.04	−6.35
	Hindu	8.33	2.251		5.97	−10.70
	No religion	9.50	3.117		5.89	−11.11
	Other	6.00	3.559		2.71	−9.29

*P < .05 level; ZBI = Zarit burden interview scale.

There were significant differences in challenges, coping and resilience among participants with different education levels. Immigrant parents with a university or higher education level had fewer challenges ($F = 10.457$; $d.f = 4, 126$; $p = .000$), better coping ($F = 10.628$; $d.f = 4, 126$; $p = .031$) and better resilience ($F = 6.989$; $d.f = 4, 126$; $p = .000$) scores (see Table 26).

Table 26

Challenges, Coping and Resilience by Educational Level

Scale	Education level	Mean	SD	F	95% CI	
ZBI	University or higher	32.63	17.330	10.457*	27.29	−37.96
	College	47.93	17.914		41.12	−54.75
	High school	51.39	18.379		44.27	−58.52
	Primary school	53.64	19.987		42.10	−65.18
	No education	60.35	13.770		53.27	−67.43
F-COPES	University or higher	108.93	26.914	10.628*	100.65	−117.21
	College	94.17	31.929		82.03	−106.32
	High school	79.68	25.601		69.75	−89.61
	Primary school	76.07	26.412		60.82	−91.32
	No education	64.71	25.680		51.50	−77.91
CD-RISC 10	University or higher	36.74	9.492	6.989*	28.82	−40.67
	College	27.03	11.227		22.76	−31.30
	High school	22.54	9.632		18.80	−26.27
	Primary school	24.21	9.569		18.69	−29.74
	No education	18.29	10.522		12.88	−23.70

*P < .05 level; ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

In terms of challenges, participants with a university or higher education level had the lowest challenges of ‘burden consequences’ ($F = 9.508$; $d.f = 4, 126$; $p = .000$), ‘burden of child’s dependence’ ($F = 7.807$; $d.f = 4, 126$; $p = .000$), ‘burden of exhaustion and uncertainty’ ($F = 8.972$; $d.f = 4, 126$; $p = .000$) and ‘burden of guilt and fear of child’s future’ ($F = 7.339$; $d.f = 4, 126$; $p = .000$) when compared with other education levels (see Table 27).

Table 27

Challenges Subscales by Education Level

Subscale	Education level	Mean	SD	F	95% CI	
Burden consequences	University or higher	20.34	8.948	9.508*	15.40	-27.28
	College	27.24	9.453		22.01	-32.46
	High school	30.00	6.099		23.60	-36.40
	No education	36.50	8.832		29.12	-43.88
Burden of child's dependence	University or higher	5.71	2.977	7.807*	4.73	-6.69
	College	6.92	2.960		6.21	-7.62
	High school	9.50	1.643		7.78	-11.22
	No education	9.25	2.765		7.94	-11.56
Burden of exhaustion and uncertainty	University or higher	7.39	4.636	8.972*	6.87	-8.92
	College	8.50	4.370		7.47	-9.53
	High school	12.83	4.708		7.89	-17.77
	No education	11.50	5.071		8.26	-15.74
Burden of guilt and fear for child's future	University or higher	5.07	2.982	7.339*	3.99	-6.95
	College	7.69	2.781		5.04	-8.35
	High school	8.33	2.251		5.97	-10.70
	No education	9.50	3.117		5.89	-11.11

*P < .05 level.

In terms of coping, the results showed that immigrant parents with a university or higher education level had significantly higher coping scores. They used more 'reframing' ($F = 9.628$; $d.f = 4, 126$; $p = .000$), 'acquiring social support' ($F = 8.928$; $d.f = 4, 126$; $p = .000$), 'seeking spiritual support' ($F = 9.028$; $d.f = 4, 126$; $p = .000$), 'mobilising family to acquire and accept help' ($F = 7.628$; $d.f = 4, 126$; $p = .000$) and less 'passive appraisal' ($F = 10.452$; $d.f = 4, 126$; $p = .000$) coping strategies (see Table 28).

Table 28

Coping Subscales by Education Levels

Subscale	Education level	Mean	SD	<i>F</i>	95% CI	
Reframing	University or higher	25.34	8.948	9.628*	23.40	–27.28
	College	21.24	9.453		18.01	–23.46
	High school	19.00	6.099		15.60	–26.40
	No education	19.50	8.832		15.12	–26.88
Mobilising family to acquire and accept help	University or higher	14.71	2.977	8.928*	12.73	–16.69
	College	6.92	2.960		6.21	–7.62
	High school	9.50	1.643		7.78	–11.22
	No education	9.25	2.765		7.94	–11.56
Seeking spiritual support	University or higher	13.39	4.636	9.028*	10.87	–17.92
	College	8.50	4.370		7.47	–9.53
	High school	11.83	4.708		7.89	–15.77
	No education	11.50	5.071		8.26	–15.74
Passive appraisal	University or higher	6.00	2.982	10.452*	3.99	–9.95
	College	7.69	2.781		5.04	–8.35
	High school	8.33	2.251		5.97	–10.70
	No education	9.50	3.117		5.89	–11.11
Acquiring social support	University or higher	27.09	9.880	7.628*	24.03	–30.43
	College	21.22	6.530		17.52	–23.98
	High school	20.94	5.174		15.23	–25.71
	No education	17.45	5.004		11.93	–19.99

* $P < .05$ level.

In terms of relationship status, the results also showed that single immigrant parents had the highest challenges ($F = 2.945$; $d.f = 3, 127$; $p = .036$) when compared with married or divorced immigrant parents. However, there was no significant difference in coping ($F = 2.164$; $d.f = 3, 127$; $p = .096$) or resilience ($F = 2.201$; $d.f = 3, 127$; $p = .091$) between immigrant parents with a different relationship status (see Table 29).

Table 29

Challenges, Coping and Resilience by Different Relationship Status

Scale	Relationship status	Mean	SD	F	95% CI	
ZBI	Single	53.66	19.888	2.945*	42.22	–65.14
	Married	47.93	17.914		41.12	–54.75
	Divorced	50.39	18.379		44.27	–58.52
	Other	32.64	19.987		27.10	–37.18
F-COPES	Single	81.93	26.914	2.164	77.92	–85.21
	Married	80.17	31.929		72.03	–78.32
	Divorced	79.68	25.601		69.75	–89.61
	Other	76.07	26.412		60.82	–91.32
CD-RISC 10	Single	31.74	9.492	2.201	28.82	–34.67
	Married	27.03	11.227		22.76	–31.30
	Divorced	32.54	9.632		28.80	–36.27
	Other	24.21	9.569		18.69	–29.74

*P < .05 level; ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

In terms of employment status, there was no significant difference in challenges ($F = 2.447$; $d.f = 2, 128$; $p = .091$) and coping ($F = 2.966$; $d.f = 2, 128$; $p = .055$) among immigrant parents with a different employment status. However, employed immigrant parents had the highest resilience level ($F = 3.447$; $d.f = 2, 128$; $p = .032$) when compared with unemployed and retired immigrant parents.

There were significant differences in challenges ($F = 3.795$; $d.f = 2, 128$; $p = .025$) and coping ($F = 4.451$; $d.f = 2, 128$; $p = .041$) among participants with different monthly household incomes. Immigrant parents with a higher monthly household income had the lowest challenges and better coping. There was no significant difference between the different household income groups in resilience scores ($F = 2.642$; $d.f = 2, 128$; $p = .075$) (see Table 30).

Table 30

Differences among Groups based on Monthly Household Income

Scale	Monthly household income (AUD)	Mean	SD	F	95% CI	
ZBI	< 5000	51.11	19.374	3.795*	43.45	–58.78
	5000–10 000	46.70	19.254		42.49	–50.90
	> 10 000	35.86	20.994		26.30	–45.41
F-COPES	< 5000	84.11	22.618	4.451*	75.16	–93.06
	5000–10 000	87.57	32.489		80.47	–94.66
	> 10 000	108.19	32.046		93.60	–122.78
CD-RISC 10	< 5000	24.22	9.597	2.642	20.43	–28.02
	5000–10 000	25.60	10.989		23.20	–28.00
	> 10 000	26.00	11.619		22.71	–30.29

*P < .05 level; ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

Table 31 shows that participants with a higher monthly household income utilised more coping strategies than participants with a lower household income.

There were significant differences in challenges, coping and resilience between immigrant parents who had different numbers of children. Participants with fewer children had significantly fewer challenges ($F = 5.268$; $d.f = 2, 128$; $p = .006$), higher coping scores ($F = 6.559$; $d.f = 2, 128$; $p = .002$) and a higher level of resilience ($F = 6.362$; $d.f = 2, 128$; $p = .002$) when compared with those who had more children (see Table 32). Immigrant parents with more children had a significantly higher level of challenges in all burden subscales when compared with those with fewer children.

Table 31

Differences in Coping Subscale among Different Monthly Household Income Groups

Subscale	Monthly household income (AUD)	Mean	SD	F	95% CI	
Acquiring social support	< 5000	23.48	7.782	5.902*	20.40	-26.56
	5000–10 000	25.76	9.873		23.60	-27.91
	> 10 000	32.57	9.923		28.05	-37.09
Seeking spiritual coping	< 5000	11.63	4.395	4.142*	9.89	-13.37
	5000–10 000	12.14	4.437		11.18	-13.11
	> 10 000	14.95	3.956		13.15	-16.75
Mobilising family to acquire & accept help	< 5000	14.78	3.876	5.922*	13.24	-16.31
	5000–10 000	11.93	4.601		10.92	-12.93
	> 10 000	16.67	4.768		15.50	-18.84
Passive appraisal coping	< 5000	9.26	4.138	6.561*	7.62	-10.90
	5000–10 000	11.40	4.633		10.39	-12.41
	> 10 000	14.00	4.393		12.00	-16.00
Reframing coping	< 5000	24.07	6.889	3.720*	21.35	-26.80
	5000–10 000	23.41	8.899		21.47	-25.35
	> 10 000	29.05	8.721		25.08	-33.02

*P < .05 level.

Table 32

Difference in Challenges, Coping and Resilience among Different Numbers of Children

Scale	Number of children	Mean	SD	F	95% CI	
ZBI	1–3	43.91	19.996	5.268*	39.11	-48.72
	4–6	45.20	19.552		39.87	-50.54
	> 6	67.25	8.294		60.32	-74.18
F-COPES	1–3	93.48	32.409	6.559*	85.69	-101.26
	4–6	91.44	27.860		83.84	-99.05
	> 6	52.88	24.608		32.30	-73.45
CD-RISC 10	1–3	28.30	11.139	6.362*	25.63	-30.98
	4–6	25.17	9.941		22.45	-27.88
	> 6	14.75	8.697		7.48	-22.02

*P < .05 level; ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

In terms of different immigration periods, there were significant differences in challenges and resilience among groups of participants with different immigration periods. Participants who had migrated to Australia for a longer period (> 10 years) had a lower level of challenges ($F = 4.245$; $d.f = 2, 128$; $p = .016$) and a higher level of resilience ($F = 4.534$; $d.f = 2, 128$; $p = .012$) when compared with participants who had a shorter immigration period. There was no significant difference in coping scores ($F = 2.978$; $d.f = 2, 128$; $p = .059$) among the three groups (see Table 33).

Table 33

Differences in Challenges, Coping and Resilience in Groups with Different Immigration Periods

Scale	Immigration period (years)	Mean	SD	F	95% CI	
ZBI	1–5	45.97	20.117	4.245*	39.36	–52.59
	6–10	50.51	19.457		45.35	–55.67
	> 10	38.42	18.881		32.03	–44.80
F-COPES	1–5	86.53	26.884	2.978	77.69	–95.36
	6–10	85.81	33.903		76.81	–94.80
	> 10	100.89	30.207		90.67	–111.11
CD-RISC 10	1–5	23.87	10.119	4.534*	20.54	–27.19
	6–10	24.88	11.287		21.88	–27.87
	> 10	30.69	10.226		27.23	–34.15

* $P < .05$ level; ZBI = Zarit burden interview scale; F-COPES = family crisis oriented personal evaluation scale; CD-RISC 10 = Connor-Davidson resilience scale.

Immigrant parents whose migration period to Australia was > 10 years had the lowest challenges in all the ZBI subscales when compared with the other two groups: ‘burden consequences’ ($F = 4.179$; $d.f = 2, 128$; $p = .017$), ‘burden of child’s dependence’ ($F = 4.325$; $d.f = 2, 128$; $p = .015$), ‘burden of exhaustion and uncertainty’ ($F = 5.347$; $d.f = 2, 128$; $p = .006$) and ‘burden of guilt and fear for child’s future’ ($F = 2.986$; $d.f = 2, 128$; $p = .050$) (see Table 34).

Table 34
Challenges Subscales by Immigration Period

		Mean	SD	<i>F</i>	95% CI	
Burden consequences	1–5	30.34	8.948	4.179*	26.40	–33.28
	6–10	27.24	9.453		22.01	–32.36
	> 10	20.00	6.099		15.60	–27.40
Burden of child's dependence	1–5	9.71	2.977	4.325*	7.73	–11.69
	6–10	6.02	2.960		6.21	–7.42
	> 10	5.50	1.643		4.78	–6.22
Burden of exhaustion and uncertainty	1–5	12.39	4.636	5.347*	7.87	–17.92
	6–10	8.50	4.370		7.47	–9.53
	> 10	7.83	4.708		6.89	–8.77
Burden of guilt and fear for child's future	1–5	8.07	2.982	2.986*	5.99	–10.95
	6–10	7.69	2.781		5.04	–8.05
	> 10	5.33	2.251		3.97	–6.70

* $P < .05$ level.

With regard to the differences in challenges, coping and resilience among different groups of parents based on their child's age and diagnosis, the findings showed that there was no significant difference among the immigrant parents with different child's diagnosis in challenges ($F = 2.554$; d.f = 3, 131; $p = .761$), coping ($F = 2.233$; d.f = 3, 131; $p = .608$) and resilience ($F = 2.320$; d.f = 3, 131; $p = .980$), or among the immigrant parents with different child's age groups in challenges ($F = 1.974$; d.f = 3, 126; $p = .080$), coping ($F = 2.754$; d.f = 3, 126; $p = .361$) and resilience ($F = 2.360$; d.f = 3, 126; $p = .669$).

4.7 Summary

This chapter reported the results of the questionnaire survey. Immigrant parents had a high level of challenges. Reframing was the coping strategy most frequently used by the parents. Parents who perceived a higher level of challenges had lower coping and resilience scores. Immigrant parents' coping correlated positively with their resilience. The next chapter will present the findings of the second phase: the qualitative interview of parents and service providers.

Chapter 5: Phase Two Results

5.1 Introduction

This chapter reports the findings of the qualitative interviews collected in phase two of the study. It first presents the themes and subthemes that emerged from the interview data, which describe immigrant parents' perception of their challenges and coping in raising their children with disabilities in a host country. This is followed by the themes and subthemes that emerged from the service providers' perception in the same regard. The subthemes are presented under each theme with the support of verbatim transcripts. Pseudonyms are used in reporting quotations.

5.2 Sociodemographic Characteristics of the Participants

A purposive sample of nine parents was recruited in phase two. Three parents had a high level of coping, three had a moderate level of coping and three had a low level of coping. Table 35 presents the parent participants' sociodemographic data. Six were mothers and three were fathers. They were of Bangladeshi, Congolese, Nepalese and Arabic cultural backgrounds. Five parents were Muslims and four were Christians. Six of them had a university or higher level of education. Five of them had a moderate monthly household income (A\$5,000–10,000). Six parents had close family and friends who lived in Australia. The participants' characteristics were similar to those in phase one of the study, aside from their education level. Most of the parents in phase two were highly educated.

Table 35

Characteristics of the Immigrant Parents (n = 9)

Demographic	Frequency (%)
Gender	
Mother	6(66.6)
Father	3(33.4)
Age	
20–30	0(0%)
31–40	4(44.4)
41–50	3(33.3)
> 51	2(22.3)
Cultural background	
Arabic	4(44.4)
Bangladeshi	2(22.2)
Congolese	1(11.2)
Nepalese	2(22.2)
Religion	
Muslims	5(55.6)
Christians	4(44.4)
Education	
University or higher	6(66.7)
College	1(11.1)
High school	2(22.2)
Employment status	
Employed	5(55.6)
Unemployed	4(44.4)
Immigration period	
0–5 years	3(33.3)
6–10 years	2(22.3)
> 10 years	4(44.4)
Monthly household income	
Low (< A\$5000)	2(22.2)
Moderate (A\$5000–10 000)	5(55.6)
High (> A\$10 000)	2(22.2)
Have family in Australia	
Yes	3(33.3)
No	6(66.7)
Coping level	
Low coping (< 50)	3(33.3)
Moderate coping (51–99)	3(33.3)
High coping (> 100)	3(33.4)

Table 36 presents the sociodemographic characteristics of each participant.

Table 36

Immigrant Parents' Characteristics

Participant's pseudonym (code)	Gender	Age	Nationality	Religion	Education	Child's age (years)	Child's gender	Child's diagnosis
Joliy (P1)	Mother	41	Arabic	Christian	University	11	Male	Autism
Lilly (P2)	Mother	43	Congolese	Christian	University	9	Female	Physical disability + cardiac disease
Mohammad (P3)	Father	42	Arabic	Muslim	University	9	Female	Physical disability + diabetes Mellitus
Jameelah (P4)	Mother	33	Arabic	Muslim	University	9	Female	Physical disability
Samreen (P5)	Mother	35	Arabic	Muslim	College	2	Male	Mental illness
Jamal (P6)	Father	53	Bangladeshi	Muslim	University	15	Female	Autism
Emmy (P7)	Mother	52	Bangladeshi	Muslim	University	15	Female	Autism
Nisha (P8)	Mother	32	Nepalese	Christian	High school	4	Female	Autism
Roshan (P9)	Father	36	Nepalese	Christian	High school	4	Female	Autism

Table 37 presents a summary of the themes and subthemes that emerged from the parents' interview data.

Table 37

Themes and Subthemes that Emerged from Interviews with Immigrant Parents

Themes	Subthemes
Ongoing challenges of everyday life	Feeling overwhelmed Being isolated due to a lack of social networks Having difficulty adapting to a new culture
Ongoing coping tactics	Seeking spiritual support Taking steps to restore control Learning how to be optimistic, positive and cheerful
Ongoing help-seeking behaviours	Seeking social connectedness Having English language skills Identifying the availability of disability services

The following presents the themes and subthemes that emerged from the immigrant parents' data with support from the participants' direct quotations.

5.3 Ongoing Challenges of Everyday Life

All the participants described the challenges they experienced while raising their children with disabilities in a host country as ongoing on an everyday basis. The three subthemes that emerged from the data were feeling overwhelmed, being isolated due to a lack of social networks, and having difficulty adapting to a new culture.

Feeling overwhelmed. Six immigrant parents reported having doubled responsibilities in their daily life due to raising their child with a disability in a host country. Jameelah is the mother of a nine-year-old girl with a physical disability. Jameelah migrated to Australia to accomplish a higher degree in a university. She also had three other children. Jameelah said that she did not have enough time to look after her daughter with a disability as well as her other children while she was a higher degree research student. She had many responsibilities as a student:

My responsibilities doubled actually. I have to give her more attention and care than her siblings. I am also a student, I moved to Australia to study, I can't ignore

that I am a student. I must manage my time between the university, my daughter, rest of my family and my house. It is really hard (p. 44, P4 [35]).

Joliy has an 11-year-old boy with autism. She shared her perception of added responsibilities in arranging and attending medical appointments for her son on top of her everyday responsibilities at home and work:

We have ongoing added responsibility. It's about making appointments, travelling to appointments, attending the appointments, going home, doing the normal routine that family do like dinners, supervising children's homework, preparing their bed, and many things to do, on top of the care for my son (p. 1, P1 [25]).

Jamal is the father of a 15-year-old girl with autism. He explained that having a child with a disability means that parents have no clear plan for their life, or for even for their day, as there are often emergency situations:

It makes me busy all the time. When you have a [normal] healthy child, you can plan accordingly, you can plan ahead, what your life will be, what will be your work. But when you have a child with disability, something might come at any time, some emergency situations. When normal healthy children are at home, you know they are doing something. But for a child with disability, you know that she is not doing anything, she always needs your help. It takes up lots of my time daily (p. 62, P6 [11]).

Roshan is the father of a four-year-old girl with autism. He described how the overwhelming responsibilities restricted his social life. Despite his busy life, he regarded his daughter as his priority. He devoted a large amount of time to her instead of going out for social gatherings.

I am not going out too much; I have only one friend, that's it, I do not have enough time to go out, I hardly go out. Many responsibilities, my work and my family, I

need to be with her more. I will not waste my time going out; I want to sit with her, teach her, she is my priority ... yes, I believe that I am isolated, but I am doing good thing for my daughter (p. 129, P9 [17]).

Being isolated due to a lack of social networks. All parent participants expressed that they had difficulties obtaining social support. Three immigrant parents who had relatives and close friends living in their community reported a lack of emotional support, love and care from both family and friends. They thought that their family and friends were unable to provide support because they also had busy lives or they did not understand or accept the child's disability. Jameelah described her experience:

Unfortunately, my extended family and friends were not actually supportive ... My family who I thought might be a little bit more understanding, were actually a bit of hindrance ... I used to be very optimistic. I thought that if people knew that I had a boy with disability, they would be more understanding, or they might be more supportive and help me when I needed. They might not physically help me. But at least, pick up the phone and call me and say hey how are you doing? What is your day like? I did not get anything like that (p. 48, P4 [22]).

Nisha, the mother of a four-year-old girl with autism, concurred:

I have some relatives live close by, but everyone is busy. They need to work as living here is expensive, very hard for me. I could not find my relative when I need them. Even if I try to ask for help, I feel that my friends and their families actually don't accept my daughter. Maybe they don't understand her, what are her needs exactly, I don't know (p. 124, P8 [13]).

Six immigrant parents who had no close family or friends in their community reported that living away from family and being disconnected from them was difficult and

that it felt like living without a backbone. Emmy is the mother of a 15-year-old girl with autism. She stated:

No one to help you, left alone with your daughter; I am very emotional, always crying, living away from my family is hard. They are my backbone, and I missed my backbone, my mum always said to me do not think stupid things, do not worry, your daughter will be ok, just keep trying. I am crying a lot (p. 126, P8 [13]).

Five immigrant parents reported being disconnected from the community due to having a child with a disability. They explained that being an immigrant parent caring for a child with a disability had a big effect on their social life. They felt very restricted. Lilly is the mother of a nine-year-old girl with a physical disability and cardiac disease. Lilly stated that she does not have family members or friends to rely on when she and her husband go out for a social event:

My social life has been affected badly. I cannot go partying. Or if my friend goes to a social event, like a birthday or maybe a ceremony, it's very hard for me just to leave the child and go, no one can take care of my child. Thus, the best answer is to say sorry I can't attend and just stay home (p. 33, P2 [8]).

Three immigrant parents reported being very selective when they were visiting other families or attending a social gathering. The participants reported that they preferred to isolate themselves to avoid any embarrassment caused by their child with a disability. Samreen is the mother of a two-year-old boy with a mental disability. She described it this way:

We are not going out that much; every outing means hard time for us. My son might put us in a very embarrassing situation. Thus, we are very selective who we will visit ... it's hard to go out (p. 77, P5 [16]).

In terms of instrumental support, immigrant parents reported challenges in the healthcare and education systems. Five immigrant parents reported that they experienced challenges in navigating the school system in Australia. Joliy said that she could understand the Australian school system, as she had been in Australia for a long time. However, she said that the disability support school system was different from the normal school system. She described it as a complicated system:

And when they start school, school has its own issues, especially in a country different from your own country, the system is different, everything is different. I am ok with the normal schools; I can understand the system, you know I have been here for a long time. But as a parent with a child with a disability, you don't know what you should do; you don't know what to do with special needs schools ... because I never had to deal with disability support schools. I did not understand how it worked (p. 5, P1 [34]).

Not all children with a disability have to enrol into disability support schools. Some children with physical disabilities such as blindness in one eye, upper and lower limb deformities, and some chronic diseases such as diabetes mellitus and heart disease can enrol in normal schools. Lilly enrolled her daughter in a normal school. She expressed that the school staff members had a limited understanding of her daughter's health condition. Mohammad is an immigrant parent with a nine-year-old girl with a physical disability and diabetes mellitus. His daughter went to a normal school. Mohammad said:

But sometimes, we found that it is hard to explain to them [school staff] the special need and her medical situation ... I can remember one of the school members did not follow my daughter's medical plan; maybe she did not know how to manage my daughter's condition (p. 39, P3 [15]).

Six parent participants expressed that the Australian healthcare system is complicated and difficult to understand. They raised concerns regarding the high number of documents that are to be updated annually, as requested by the healthcare system. They said that the documents were very difficult to understand. Further, they reported long waiting lists. Mohammad described the Australian healthcare system:

Healthcare system in Australia is complicated; it has long queues, long waiting lists, many documents needed to be completed by parents to prove what support services or what therapies she needs and how much funding she needs to be able to continue this [support provided by services] ... need to renew every year, many referrals, from general practitioner to specialist, and from specialist to another, really confusing and time-wasting (p. 130, P9 [5]).

Joliy reported that sometimes healthcare professionals provided the parents with conflicting information and they did not provide the parents with a feedback regarding what they are doing good for their children. She considered it a challenge:

We received sometimes conflicting information from service providers, which I am sure is a challenge for all families if they have such conflicting information. I remember a service provider suggested me to use both languages, English and Arabic, to communicate with my son. Then in the next appointment, another service provider advised me not to use two languages as it would cause confusion for my son and would delay his language. Which advice is the right one? What should I do? Am I bringing a hindrance in my child's development or am I helping? I did not receive any feedback from them. That was definitely an issue (p. 6, P1 [35]).

Having difficult adapting to a new culture. Culture is defined as the characteristics and set of knowledge of a particular group of people, including their language, religion, values, food, social habits, music and arts (Zimmermann, 2017). As the

immigrant parents had their own culture, they reported challenges in having migrated to a host country with a new culture. Muhammad explained how it was difficult at times to enrol his daughter with a disability in sporting activities due to cultural issues, such as going to mixed-gender swimming pools:

She likes swimming. We attended about five swimming classes, we found it hard for us to continue. Because in our culture, we would not go to mixed-gender swimming pool like in here. Her swimming pool have boys and girls together. In our country, there was a separate swimming pool ... she is not going for swimming anymore. She always wants to go but it's hard, we cannot accept that (p. 53, P3 [23]).

Samreen voiced that the Australian culture is different from her culture in terms of requesting help from neighbours:

Raising a child with a disability in a different culture is very hard. In the culture where I come from, if I have a child with disability, my neighbour would look after the child. Everyone in the community live like they are related to one another. They help one another. It's not my burden alone. But the Australian culture—even neighbours don't know each other; I can't change their culture (p. 73, P5 [17]).

Immigrant parents in this study considered language to be an important part of their culture. Immigrant parents raising children with autism reported that other siblings in the family were able to learn and communicate in two languages: English and their native language. However, they had to drop their native language for their children with disability and communicate with them using the English language only, as advised by the treatment care team. By dropping the native language, immigrant parents felt that they had dropped an important part of their culture. Emmy stated:

We had to drop the Bengali language and focused on English only. It was a hard thing to do because I was raised in a family where we spoke two languages and I

wanted the same for my daughter and for my children. But we had to focus on one language (p. 121, P7 [21]).

Immigrant parents who participated in the current study reported language barrier as a factor preventing them of getting better education or employment. They described the English requirement for the Australian employers for hiring people as high. They also reported being requested to be highly proficient in English to be accepted in educational courses such as university level courses, Roshan said:

Last year, I was thinking of improving my social status, to get better income, I tried many times to apply for different jobs, like maintenance officer and road constructions but always I am stuck in the English requirements. My English is good but not up to their[Australian employers] standards. So, I've tried another way, to do university, getting certificate first then finding a job. But, again they required high proficiency in English for enrolment which I can't get. It is like a closed circle (p. 128, P10 [17]).

Immigrant parents who participated in the current study were proficient English speakers. However, they still reported language challenges in the healthcare context. They felt that jargon used by healthcare professionals was incomprehensible. Mohammad stated: 'I find it difficult sometimes to understand some terms used by physicians or nurses, there were terms that we could not understand' (p. 49, P3 [23]).

The immigrant parents found themselves unable to explain to healthcare professionals their child's health situation in English. Lilly said:

There are things I could express them well in my mother tongue, but not in English. When I need to explain what's going on with my child sometimes, I could not explain accurately because I don't know which word to use. Thus, language is a barrier to me (p. 26, P2 [11]).

However, Jameelah appreciated the interpreting services that were provided on request: 'I don't find any difficulties in medical appointment because always there are interpreters available to help; face to face or over the phone' (p. 51, P4 [19]).

5.4 Ongoing Coping Tactics

Immigrant parents reported utilising different tactics to cope with their everyday challenges and lighten their burdens. Three subthemes of coping emerged from the data: 'seeking spiritual support', 'taking steps to restore control' and 'learning how to be optimistic, positive and cheerful'.

Seeking spiritual support. Four immigrant parents sought spiritual support through praying and attending religious activities when faced with challenges in raising their child with a disability. Lilly said:

We cope by faith. Because we are believers. We are religious people. We believe that there is a God. And that really gives us strength to live another day. Every day we kneel to pray. And we hope that God will pour His pity on this little child. That's our strength that makes us carry on. Without that, it would be very difficult. I belong to a group of believers. We meet and we pray. Sometimes, if I feel like my burdens are too heavy, I will go to the meeting in my community. It lightens my burdens (p. 17, P2 [10]).

Jamal described how his faith makes him stronger:

First of all, I am a Muslim, so I ask Allah to support me and help me with my daughter. Because I have a faith to help me, this is really big thing that supports me. And help me to overcome all these challenges. Oh, Allah, you have given it to me, now give me the strength. Then, he will give you the strength. I believe in Allah. I must be patient to be rewarded Aljannah [paradise]. My faith always reminds me

about the other life and the rewards that I will get from Allah because I manage and nurture a child with a disability to grow properly. My faith makes me stronger (p. 69, P6 [22]).

Taking steps to restore control. Four immigrant parents described the effort required to confront and manage their challenges. This included looking for more information to solve their problems and putting strategies in place to prevent or manage potential challenges. Roshan stated:

Being immigrant parent in a country not your own country, taking care of a child with disability, it's about learning and gathering information as quickly as you can and trying to keep up to date with that information. Keeping up to date with good services, knowing where I could find the right service for my child. What supports do I have as a parent of a child with a disability? Who should I go to? Then put the plan and start to fix everything (p. 131, P9 [19]).

Nisha added:

For sure we do have challenges but always we have strategies and plans to manage them. I will give you a quick example. Because we know that we have a sick child and we need to adjust according to her needs and our needs. We have to come in the middle of somewhere that we also fulfil our need in some parts and her need in some parts. So, always plan. We manage with our friends, who accept us. If someone does not like my child, I do not even go near them. Because there is no point. I will only accept the friends who accept my daughter. This is my strategy to overcome the barrier in social life (p. 126, P8 [2]).

Jameelah reported time management as a strategy she often used to manage her challenges. She said:

I try to manage my time. I make a list and write everything in a diary. This really helps me. When I know that I accomplished tasks, I feel more comfortable. That reduces the stress. When I feel comfortable, I can give more. When I feel stressed, I cannot. I feel nervous. This really helps me. Managing my time (p. 44, P4 [22]).

Learning how to be optimistic, positive and cheerful. Three immigrant parents reported that having an optimistic, positive personality was an effective strategy to manage their everyday challenges. Jamal described:

I always look at the positive side. For negative things, I just put them aside. I think it is the best way to deal with problems. If there is a problem in life, not only a sick child, you need to think about what is positive in that problem and turn the negative side to positive. Then you will not feel frustrated, or too hard. The problem then appears not that challenging. Because you make it easy (p. 68, P6 [17]).

5.5 Ongoing Help-Seeking Behaviours

The immigrant parents reported seeking external help to assist them to be more resilient. Three subthemes emerged from the data: ‘seeking social connectedness’, ‘having English language skills’ and ‘identifying the availability of disability services’.

Seeking social connectedness. Five immigrant parents reported that they coped well and felt more resilient by connecting to people in the same situation and to healthcare professionals. It assisted them to overcome their challenges. Attending support groups to meet immigrant families that have children with disabilities was reported by Joliy as very helpful: ‘I remember attending a support group, and at the support group I met a parent who gave me information that nobody else could give me. This is really helpful’ (p. 8, P1 [19]). Support groups are helpful for the children with disabilities as well as for the parents. Mohammad said:

It's a good opportunity for my daughter to know that she is not the only one who has disability. There are someone else here, and all of them they get the same care, same support. Also, she related to other kids with similar condition, which is something good for her. They found themselves in the same situation. They feel comfortable. More comfortable (p. 9, P1 [15]).

Many immigrant parents expressed the value of professional support. Jameelah stated:

The support provided by medical staff is helpful to us as a family. They made couple of appointments to check what exactly is going on with my daughter. They provided us with all the information that we need. We were provided with instructions and training for equipment that my daughter use. Really, I appreciate the medical team's support (p. 49, P4 [13]).

Having English language skills. Five immigrant parents reported that fluency in English is helpful and makes them more resilient. Jamal stated:

I believe that if you have the English language proficiency, everything become easier. I am probably a little bit more fortunate because I can communicate in English well, that helps me a lot honestly. I know some friends are suffering because they are not good English speakers (p. 85, P6 [21]).

Identifying the availability of disability services. Six immigrant parents explained that the availability of disability services such the NDIS positively affected their experience. Immigrant parents reported the difficulty they faced before being enrolled in the NDIS. However, they appreciated the support provided by the NDIS and their service providers, which makes their life easier. Joliy said:

It's not easy raising a child with a disability in a host country. Our life was very hard before getting the disability services, feeling like no guidance, not enough

information and no support, 'specially in the financial side. And to be honest, it is not an easy to be recognised by the NDIS; it took me about one year to enrol my son in the NDIS after providing a lot of documents and wait for long time. But when we enrolled in the NDIS, life started to be easier. They supported us with different services such as physiotherapy, speech pathology and school for special needs. Having supportive service providers who working with you is important. You cannot raise a child without using some services that are designed and specialised in disabilities (p. 5, P1 [10]).

Mohammad described how the availability of NDIS support made their life easier: *Good services made my challenges easier. Availability of equipment that required for my daughter to give her good quality of life, like walking aids, is really an amazing part. The equipment is available with a very low price. The cost is reduced so much from hundreds to tenth. Also, the financial support from NDIS gave support for my child with disability (p. 37, P3 [16]).*

5.6 Service Providers

A total of nine service providers were interviewed. Table 38 presents the service providers' sociodemographic data. All the interviewees were case coordinators for the NDIS. Five were females and four were males. They were from different cultural backgrounds. Four of them were born in Australia. Seven of them were Christian. Six of them were 41–50 years old. Eight of them had more than five years' experience as service providers working with immigrant parents raising children with disabilities.

Table 38

Characteristics of the Service Providers (n = 9)

Demographic	Frequency (%)
Gender	
Male	4(44.5)
Female	5(55.5)
Nationality	
Australian	3(33.3)
Arabic	3(33.3)
Afghani	2(22.3)
Netherlander	1(11.1)
Religion	
Muslim	2(22.3)
Christian	7(77.7)
Age	
20–30	0(0%)
31–40	2(22.2)
41–50	6(66.6)
> 51	1(11.2)
Immigration period	
Born in Australia	4(44.4)
0–5	0(0%)
6–10	2(22.3)
> 10	3(33.3)
Position in work	
Case coordinator	9(100%)
Years of experience	
1–5	1(11.2)
5–10	3(33.3)
> 10	5(55.5)

Table 39 presents a summary of themes and subthemes that emerged from the service providers' interviews.

Table 39

Themes and Subthemes that Emerged from Service Providers

Themes	Subthemes
Barriers	Perceived barriers to establishing social networks Perceived barriers to utilising available disability services
Facilitators	Services with competent staff Availability of social support networks Steps to take over own control

The following presents the themes and subthemes that emerged from service providers' data with support from the participants' direct quotations.

5.7 Barriers

Service providers reported various barriers that hindered immigrant parents' coping processes while raising their child with a disability in Australia. Two subthemes emerged from this theme: 'perceived barriers to establishing social networks' and 'perceived barriers to utilising available disability services'.

Perceived barriers to establishing social networks. Five service providers reported that immigrant parents raising a child with a disability are socially isolated due to various factors. Jinny, who is a case coordinator with 13 years' experience, explained:

If you have a child with special needs or disability, you tend to find that you are confined at home because it is difficult to go out with your child. Because you don't know how your child will react in an unfamiliar environment, or maybe you know that your child does not like to be around by other people. So, you are not going to put yourself in that position where you are going to visit a family knowing that your

child is going to be noisy, destructive, crying ... behaviours that the child may show when they go out (p. 36, S6 [23]).

Salma is a case coordinator with three years' experience. She said:

Parents thought it is a shameful thing to have a child with disability, and they try to hide it. It is something regarding their culture It is too embarrassing to talk to other people, or to tell people that I have a child with a disability ... they are embarrassed to take them out to public places, depending on child's disability. If it is an obvious disability or the child will make a lot of noises, the parents regarded it as an embarrassment (p. 43, S7 [6]).

Nick, who is a case coordinator with nine years' experience, supported this:

What I felt is, which is purely based on my observations; some families feel a kind of shame to disclose one of the family members has disability. Another very strong factor that I felt is a kind of shame in approaching someone for help in this matter. It will be easy for them to approach Centrelink, which is the service for social security payment for financial help. They do struggle in disclosing the disability of a family member, even sometimes for their family doctor or their healthcare professionals (p. 66, S9 [7]).

Sam, who is a case coordinator with 17 years' experience, said that the responsibilities of taking care of a child with a disability were the major factor in parental social isolation:

Children with disabilities need a lot of care and anyone taking care of them have lots of responsibilities. It is hard for parent to find someone to take care of his or her child with disability when the parent is out. I will give you an example: If you feel like going out for a coffee with your friend, you just pick up your car keys and the next thing is you park your car and then you are sitting in the café, you are

laughing and enjoying a nice cup of coffee with your friend. If someone with a child with disability wants to attend the same gathering, they start thinking about it few days ahead. Who they will give their responsibility to, what will happen if the child's condition deteriorates, how would they approach the emergency service? Further, have they got enough money to pay someone to take care of the child at home? In many cases, the parents will choose to stay home and will save them from all that trouble (p. 12, S2 [7]).

Christian, who is a case coordinator with six years' experience, summarised the barriers:

It's hard enough to be isolated because of language issue, and being in a new country, they are unfamiliar with the new environment and they are scared of integrating and interacting with people in their community, even within their own community. They have a lot of things to do, many responsibilities. It's very challenging (p. 20, S3 [15]).

Perceived barriers to utilising available disability services. Service provider participants believed that the Australian healthcare system is complicated. However, four of them expressed that the immigrant parents did not have a good understanding of the available services. Thus, they did not use the service, refused the service or cancelled their children's medical appointments. Christian stated: 'Parents don't understand the importance of these weekly appointments such as occupational therapy, speech therapy and physiotherapy. Because they don't understand how it benefits the child, they asked whether they really need this appointment?' (p. 17, S3 [11]).

Nick supported this:

Lack of understanding of our services is a challenge. For example, I had a mother who said to me, the service providers came and they spent half a session talking to

me and half a session working with my child. She said she did not want them to talk to her. She wanted them to give all the time to her child. But I had to explain to her that it is not how it worked. They need to talk to her. They are trying to explain to her, what they are doing ... if there are elements or aspects that she could implement and practice throughout the week as a parent in between appointments. The parents don't understand that (p. 66, S9 [12]).

Nelly, a case coordinator with 13 years' experience, added: 'I am seeing the parents, who are the primary carer, really looking burnt out and may not know about the respite services that could really improve the family's life' (p. 28, S5 [21]).

Saleem, a case coordinator with seven years' experience, perceived the immigrant parents' culture as a challenge. He stated:

The other aspect is their cultural norms that kicked in ... some parents' culture is not to ask for more information, not to ask someone for help, they only stay at home. Those parents are not aware of their rights ... they are hesitated to use the healthcare services because they thought it will cost them money ... they even did not know that it is free for them ... they need to be educated about their rights (p. 40, S7 [15]).

Jinny concurred:

Values and beliefs of parents' culture are issue at times. They are scared. They are traumatised. Even if you make them aware of their rights, they might feel reluctant to stand up and say that this is my right (p. 38, S6 [10]).

All service providers reported language, which is a part of parental culture, as a barrier. Helen is a case coordinator with 12 years' experience in providing care to immigrant families from different backgrounds. She stated that the language barrier is the biggest challenge for the parents:

I think the first thing that I have to say without a doubt is the language. The biggest burden they have, or the challenge of raising your child, is the language barrier. It makes it very difficult for parents to obtain information and to understand the information about the different services available and the policies of those services. If they go to a service and they are given information to help them to work with the child, this is always done in English. Language is a huge challenge (p. 3, S1 [1]).

5.8 Facilitators

Service providers described factors that enabled the immigrant parents to overcome their challenges and cope well. Three subthemes emerged from the data: ‘services with competent staff’, ‘availability of social support networks’ and ‘steps to take over own control’.

Services with competent staff. Six of the service providers believed that the availability of disability services and competent staff, who understand the immigrant parents’ needs and support them to make the right decisions, is a major factor that can make immigrant parents’ challenges easier. Saleem said:

I think services like NDIS that will give them multiple advices related to their issues. That will create many choices and will make their life easier. They are not in the right frame of mind to make a right decision. You need qualified service providers with good communication and good skill sets such as patience, understanding, good listening and critical thinking who can help those parents. I believe that the good service with the good staff can make a difference in those parents’ life (p. 43, S7 [23]).

Nelly stated that language was the main barrier limiting the immigrant families' caring of children with disabilities and that the provision of bilingual service providers would be very beneficial to the immigrant families. She said:

Language is the first challenge, no doubt. Having bilingual workers that can work and support families through their appointments with the therapists and with NDIS is very beneficial for the families. It makes things easier for families. The benefits of information and services that they receive were maximised (p. 28, S5 [13]).

Availability of social support networks. Six service providers perceived social support provided by family members, the community and healthcare professionals as a facilitator for parents. Salma stated:

Parents are coping well if they are a big family. It is very useful, especially if they have a child with disability; having a big family can be very useful because everybody gets involved in helping and raising the child or supporting the child with disability (p. 45, S7 [13]).

Sam reported:

It is important to have groups from their own culture and they help each other. They are linking themselves with people of similar culture and I think it does help. For example, there are 10 Afghani families took the services; they mentor the other new Afghani families. You need to identify a leader in the groups who can help them and who speak better English (p. 14, S2 [10]).

However, Jinny thought that being introduced to other families from their own culture is a sensitive part of the coping process:

I believe that engaging immigrant families with people from their same culture is a good idea. But introducing them to other people from the community or other families that might have a child with disability from same culture is not easy. We

need to be cautious and do it in a very sensitive way. Because, as I said, some don't want other people to know that they have a child with disability. We have to be very sensitive to how they feel, what they want and what they do not want. And a simple conversation can answer a lot of those questions (p. 38, S6 [15]).

Nelly added:

I think immigrant parents who are seeking help and support from organisations like NDIS definitely help them to cope well. I think immigrant parents are seeking support and help from qualified service providers who have good communication and knowledge. Added to that, holding educational and training sessions is helpful for parents to provide them with the needed information and to give them the chance to ask questions (p. 29, S5 [18]).

Steps to take over own control. Three of the service providers perceived that parents who took control of their situation had better problem-solving techniques and those with a willingness to learn more about resources and services coped better. Alfred, a case coordinator with 14 years' experience, stated:

Parents who have their own plans, who are aware of what systems are in place, who are willing to find alternatives and right information, who prioritise their duties, know ways to access to services or care structure provided by the Australian government, have better coping (p. 70, S9 [19]).

Sam added:

Generally, those families who are active, who do things, go out into the community and integrated with members with the communities, cope much better. Not necessarily with other cultures, but at least they are getting out, going to park on the weekend, or they are taking their child to a sporting and recreational activity.

Families who face the problem, try to fix it, are those who cope better because they are confident, they obtain information, they are asking questions and they are trying to get what they can (p. 14, S2 [7]).

5.9 Summary

This chapter presented the themes and subthemes that emerged from the qualitative interview data of immigrant parents and service providers. Immigrant parents reported feeling overwhelmed, being isolated due to a lack of social networks and having difficulty adapting to a new culture as the main challenges in their experience of raising a child with a disability in a host country. Immigrant parents used different coping tactics, including seeking spiritual support, taking steps to restore control and learning how to be optimistic, positive and cheerful. They perceived seeking social connectedness, having English language skills and identifying the availability of disability services as factors that help them to be more resilient. Service providers reported perceived barriers related to immigrant parents' coping, including establishing social networks and utilising available disability services. Service providers regarded services with competent staff, the availability of social support networks and steps made by immigrant parents to take over their control as facilitators that assisted the immigrant parents to cope with their situation and overcome their challenges. The findings show that immigrant parents and service providers shared some common perceptions, as well as different ones, on parental challenges, coping, facilitators and barriers when raising a child with a disability in a host country.

Chapter six will integrate the findings of the studies from phases one and two and discuss the findings with support from the literature. It will also present the implications and conclusion of the study.

Chapter 6: Discussion

This study examined the challenges, coping and resilience of immigrant parents of children (0–18 years old) with disability. The study was the first of its kind conducted in Australia. This chapter integrates and discusses the findings from Phases 1 and 2 with support from the literature. The limitations are addressed; followed by the findings' implications for policy, practice and research; and concluding thoughts.

6.1 Aims and Research Questions

The research questions that guided this study were:

6. What do immigrant parents raising children with disability in Australia perceive as everyday challenges?
7. What are the coping strategies used by immigrant parents to overcome these challenges?
8. What is their level of resilience?
9. What are the relationships among challenges, coping strategies and resilience?
10. What are the perceived barriers and facilitators of coping among parents of children with disability?

The aims of the study were addressed using a mixed methods design, specifically, a two-phases sequential explanatory mixed methods design was used. Phase 1 of the study involved a cross-sectional survey of 134 immigrant parents, with the findings presented in Chapter 4. Phase 2 of the study adopted face-to-face semi-structured interviews of nine immigrant parents recruited from the Phase 1 survey participants, and nine NDIS service providers providing care for immigrant families with children with disabilities. The Phase 2 findings were presented in Chapter 5.

6.2 Response Rate

This study had an overall response rate of 56.5%, with the response rate of both study sites being similar (Sydney 57.3% and Newcastle 55.9%). The response rate was higher than some previous studies (e.g., Steiner & Landös, 2019; Straiton, Aambø & Johansen, 2019). The comparatively high response rate in the present study could be due to the study venues in two major Australian cities hosting a high immigrant population, the researcher's own connection and presence to the study venues, and the support and cooperation gained from NDIS case managers.

6.3 Participants Profile

Most participants in this study were mothers ($n = 84$, 62.7%) aged between 31 and 40 years, which was similar to previous studies. For example, John, Bower and McCullough's (2016) study conducted in the US found that more mothers participated in studies than fathers. Traditionally, mothers are the main caregiver in the family. In the present study, 50 fathers (37.3%) participated in Phase 1 and three fathers (33.3%) in Phase 2. This might indicate that more fathers are playing a major role in the caregiving responsibilities of children.

One of the current issues around NDIS is the inadequate attention paid to both parents in the family. In most cases, the term 'family' or 'parents' meant only mothers, not fathers (Strohm, 2017). A previous study examined the differences between the challenges of fathers and mothers in taking care of their children with disability and found that mothers perceived higher challenges and more burden than fathers (Rowbotham, Carroll & Cuskelly, 2011). Thus, more interventions from disability services are provided to mothers.

Conversely, the present study (Phase I survey) found that immigrant mothers and fathers faced very similar challenges in raising children with disability, meaning that

immigrant fathers may be heavily involved in child caretaking responsibilities. The qualitative data shows that immigrant fathers focused on the issue of social isolation more than immigrant mothers, reporting that raising a child with disability along with their other responsibilities impacted fathers' social life and made them very socially restricted and isolated. Though there was no significant difference in challenges among fathers and mothers in the quantitative findings, the qualitative interviews found that immigrant fathers perceived different challenges when raising children with disability.

Fifty-seven (42.5%) of the participants had been in Australia for 6–10 years (average of eight years), which was considered a relatively long time. These findings matched those of Al-Azzam's (2011) study conducted in the US (average residency period of participants was eight years). In the present study, 38 participants (28.4%) had been in Australian for less than five years. This could be due to recently arrived immigrant parents being less fluent in English and, thus, not joining the study. This is potentially a limitation of the current study. Immigrant parents less fluent in English might have different challenges than those fluent in English.

There were significant differences in challenges among the groups of participants based on immigration period. Participants who had resided in Australia for a longer period (>10 years) had a lower level of challenges compared to participants with a shorted residency period (1–5 years) and (6–10 years). Parents who had resided in the country longer may have more time to find resources to support their caregiving responsibilities. Thus, immigrant parents who are new to the country may need extra support for their caregiving responsibilities and integration into the host country.

Immigrant parents who have resided in a country for a longer period may be assumed to know more about the social context, healthcare and education system of their host country (Miglietta & Tartaglia, 2009). However, long-term residency participants in

the present study still found it difficult to navigate special need schools and disability services with which they were not familiar, despite generally having been in Australia for over eight years. Therefore, no assumptions should be made as to immigrant parents' needs based on immigration period.

Of the study participants in the present study, 54.5% (n = 73) were of Arabic origin and 53.7% (n = 72) were Muslims, with most having immigrated from Lebanon, Syrian and Iraq. Immigrants of Australia came from the top five countries of origin - the UK, New Zealand, China (excluding Hong Kong and Taiwan), Italy, and Vietnam - account for 45.1% of all the immigrants in Australia (Migration Policy Institute, 2019). The NDIS centres that consented to participate in the study are located in Newcastle, Bankstown, Fairfield and Liverpool areas in New South Wales. The immigrant population of these areas are mostly of Arabic origin and immigrated to Australia for humanitarian reasons. This was the reason that the majority of the participants in this study were of Arab origin.

From 2016–2017, Australia received 13,750 immigrants for humanitarian reasons due to political conflicts, especially from Iraq, Syria, Lebanon, Afghanistan, the Democratic Republic of the Congo and other African countries. This number increased to 18,750 in 2019. By 1 October 2019, 23,370 applications for immigration had been approved by the Australian Department of Home Affairs (Refugee Council of Australia, 2019). Approximately 70% of Arab Australians are Muslims (Australian Human Rights Commission, 2003). The high number of immigrants of Arabic background in the recruitment areas meant that the majority of study participants were Arab and Muslim. This raises the issue of potential selection bias in the present study.

Results showed no significant difference in challenges, coping and resilience scores between groups with different nationalities at birth. However, there were significant

differences in perceived challenges between immigrant parents with different religions. Muslim immigrant parents had the lowest perceived challenges. Muslim parents might perceive a child's disability as a test of their faith in God/Allah and, thus, endeavour to be understanding and patient so God/Allah will reward them with Paradise (Attum, Waheed & Shamoon, 2020). Taking care of children with disability with this mindset may have made Muslim participants perceive less challenges. Immigrant parents with no religion had the highest overall ZBI scores and all subscales except burden of 'exhaustion and uncertainty'. Klocker, Trenerry & Webster (2011) highlighted in their study the impact of 'no religion' status on the high level of challenges among carer of relatives with disability. They reported that people usually translated their religious beliefs and practices to cope with life challenges in caretaking of their relative with disability. However, carers with no religion had increased risk of negative mental health which lead to high level of challenges (Klocker, Trenerry & Webster, 2011). In the current study, immigrant parents with no religion had the highest overall ZBI scores. Due to the small number of participants in this group 6% (n=8), it is not possible to draw conclusion on the relationship between religion and perception of challenges. Future study with bigger sample size in the no religion category will provide more conclusive findings.

Comparisons of socio-demographic data were made between study participants and the general Australian population using ABS (2017) Census data. For marital status, 82.8% (n = 111) of study participants were married, which was much higher than that of the general population (48.1%). This is likely due to most immigrants immigrating as a family. For education, 32.1% (n = 43) of study participants reported completing higher education, slightly higher than the general population data (30.9%). This is likely due to higher education being advantageous in the immigration process, particularly for the purpose of working (ABS, 2019). For employment, 49.3% (n = 66) of study participants were in the

labour force, lower than the general population (57.7%). Although the immigrant population of this study had a comparatively higher education level than the general populace, they had a lower employment rate. The present study did not explore the reasons for the participants' higher unemployment rate. The literature suggested a variety of factors that might contribute to the higher unemployment rate experienced by some immigrant groups, including immigrants' human capital (the skills, knowledge and experience possessed by an individual or population viewed in terms of their value or cost) not being valued by the host country, language and religious differences that make it difficult to find employment, language difficulties, or discrimination (Drinkwater, 2017). In the present study, it could be related to the need of taking care of the child with disability at home. Future studies could further examine reasons for higher unemployment rate of immigrant parents with children with disabilities.

For total monthly household income, 61.9% (n = 83) of study participants reported moderate (A\$5,000–10,000) monthly income (average of A\$7,500), similar to that of the general Australian populace (A\$7,000). The present study showed that unemployed immigrant parents generally had a similar monthly household income to the employed population. This is likely related to the Australian Government's financial support for immigrants. Each unemployed immigrant parent receives a A\$452.30 fortnightly payment, a maximum of A\$186.20 fortnightly for children up to 12 years old, and A\$242.20 fortnightly for children from 13 to 19 years old (National Commission of Audit, 2019). The NDIS also supports children with disability and their carers financially. For example, on average, a child with autism who is an NDIS participant receives A\$32,800 annually for disability services (NDIS, 2019). Such financial support may be the reason why financial problems were not mentioned in the present study, as opposed to previous studies

(Alvarado, 2004; Narayan, 2015). It appeared that immigrant parents in the present study were provide with adequate financial assistance by the Australian government.

Most of the children with disability in the current study were aged between 6–10 years old and were mostly diagnosed with a physical disability. This is similar to the profile of children with disabilities in Australia in general, with the highest disability prevalence in those aged between 5–14 years old (ABS, 2019). This prevalence in school-age children could be related to disabilities such as autism and learning disabilities not being recognised until children reach school age, when social demands, such as those related to schooling, become greater (Australian Institute of Health and Welfare, 2017).

6.4 Key Findings

The results of the Phase 1 survey and Phase 2 interviews are integrated into five main key findings:

1. 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.
2. 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.
3. 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.

4. 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.
5. 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.

Table 40 presents the relationship of these key findings with the research questions and their alignment with Phases 1 and 2 of the study. These key findings are discussed in the following sections.

Table 40

Relationship of key findings with the five research questions and alignment with Phases 1 and 2 of the study

	Key findings	Finding aligns with						
		<i>RQ1</i>	<i>RQ2</i>	<i>RQ3</i>	<i>RQ4</i>	<i>RQ5</i>	<i>Phase 1</i>	<i>Phase 2</i>
1.	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.	X					X	X
2.	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.		X				X	X
3.	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.			X			X	X
4.	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.				X		X	
5.	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.					X		X

Note: RQ = research question.

6.5 Challenges of Immigrant Parents Raising Children with Disability

More than half of the immigrant parents raising their children with disability in the current study ($n = 75$, 56%) experienced moderate to severe level of challenges (ZBI range 41–88, Mean = 45.73, SD = 20.14). To the best of researcher's knowledge, no quantitative study has previously been conducted using ZBI to measure the level of challenges among immigrant parents raising children with disability, thus the results could not be compared to previous studies. However, the scores obtained from ZBI in the present study were considered high. These challenges are discussed below.

6.5.1 Overwhelming caretaking responsibilities

Among the ZBI subscales, the present study showed that the subscale 'consequences of caregiving' had the highest score. The highest scoring ZBI item was 'feel stressed between caring for your child and trying to meet other responsibilities for your family or work'. The quantitative findings were supported by qualitative data. Both immigrant parents and service providers perceived overwhelming caretaking responsibilities as the greatest challenge for immigrant parents raising children with disability while so looking after the whole family and other aspects of their life. These findings are consistent with the findings of Stevens's (2010) study that suggested care responsibilities as the main challenge for immigrant parents raising children with disability. However, Stevens (2010) reported immigrant mothers, not fathers, as experiencing a loss of their own lives due to overwhelming responsibilities because fathers left caregiving responsibilities to their wives; thus, mothers tended to carry the bulk of caregiving responsibilities.

In the present study, both immigrant mothers and fathers reported being overwhelmed by raising the children with disability, indicating that fathers were also involved in the caretaking process. The traditional sex-typed division of labour (gender roles), with women serving as homemakers and caretakers and men serving as providers

and protectors, has evolved, and these gender roles are influenced by culture and context (Zhu & Chang, 2019). The participants of the current study are living in a safer and more stable society in Australia that might foster modernised gender roles and encourage fathers' involvement in family caretaking responsibilities. Thus, the fathers in the present study shared the child caregiving role with their wives.

The challenges of immigrant parents may be exacerbated by having more than one child in the family. Fifty-four (40.3%) participants had four to six children. Immigrant parents with less children (one to three children) had significantly less challenges compared to those with large families (four to six children). Immigrant parents with more children seemed to be more overburdened by the demands of raising their children, such as helping with homework, handling the logistics of after-school activities, sports and doctor's appointments. More importantly, they had to assist their children to settle in the host country and adopt the new culture (Khanlou, Haque, Sheehan & Jones, 2015).

Previous studies concur that immigrant families with more than child (not necessarily with disability) experienced more challenges in their daily life due to high demand of their large family (Mynarska et al., 2015). It seems that large immigrant families face compounded challenges due to the demand of more family members. Thus, large immigrant families raising multiple children with disabilities require more support and attention from service providers.

6.5.2 Lack of supportive social networks

Lack of supportive social networks was perceived as a significant challenge by immigrant parents. This was supported by both quantitative and qualitative findings. These findings agree with Shtutman's (2015) study that immigrant parents struggled without a support system to help in raising their children with disability.

Social support has increasingly been recognised as an important source of support for people with stressful life situations (Filipič Sterle, Vervoort & Verhofstadt, 2018). Social support is commonly categorised into four types. Emotional support is the expressions of empathy, love, trust and caring provided by others (Reis, Clark & Holmes, 2004). Instrumental support refers to assistance received from others that is tangible (Brown, Nesse, Vinokur & Smith, 2003). Informational support is the advices, guidance and suggestions provided by agencies, institutions or services to a person (Uchino, 2004). Appraisal support refers to the information provided by service providers, family members or friends that is useful for self-evaluation (Uchino, 2004).

Being immigrant parents living away from their extended family was a perceived challenge of participants in the current study. Family is considered a primary unit of society and extended family members are usually a source of emotional and instrumental support for other family members (Khanlou et al., 2015). When extended family members live overseas, they cannot contribute effectively to emotional or instrumental support for immigrant parents in raising children with disability. In the present study, 59.7% ($n = 80$) of parents reported not having extended family in Australia, while 15% ($n = 20$) reported having extended family members and relatives in Australia. Yet, no significant differences in their challenges were found between these two groups as both reported not receiving enough support from their families.

In the current study, participants who did not have extended family or relatives in Australia did not have relatives to rely on and also could not find support from their community and neighbours. Participants believed that in the Australian culture it is not acceptable to ask help from a neighbour to help with a child with disability, as opposed to in other cultures such as Middle Eastern culture.

Interestingly, immigrant parents in the current study who had extended family members and relatives in Australia also reported a lack of emotional support from their

relatives. Their relatives might be unable to provide support to them due to the pressure of life in Australia. The participants expressed that their relatives had their own responsibilities or jobs and, thus, had no extra time to support the immigrant parents in raising children with disability.

This finding is different from many studies conducted in the US that suggested social support from family members and extended family was the first line of support for immigrant parents (John et al., 2016; Lee & Park, 2016). This difference might be related to the host country's culture. This also highlights the importance of finding alternative support resources for these parents. Immigrant parents need to be directed by service providers to engage in support groups where they can meet other families experiencing the same situation to compensate for extended family separation and/or lack of family support. Further, these parents need to be directed by service providers to appropriate disability services that can help in providing instrumental support when needed such as the respite care and childcare.

In terms of informational support, participants considered the healthcare and educational system as complicated and difficult to navigate. They also perceived not receiving enough information about the available resources and services for their children or even for them as parents. Hence, they were unable to access adequate informational support. However, service providers in the presented study expected immigrant parents to understand the disability services available. Some services were introduced to parents by the service providers, but the parents did not attend or refused the services because they did not understand the importance of the services. Service providers perceived parents' culture (values and beliefs) as an obstacle to them being aware of their rights in accessing disability services, and thus a barrier to accessing disability services. The differing perceptions of immigrant parents and service providers could be a barrier to parents receiving support. Providing information about disability

and healthcare services and their availability, as well as explaining the function and importance of the services are crucial determinants for immigrant parents to take an active role in the care process and obtain appropriate help (Alsem et al., 2017).

However, research has shown that some healthcare providers are not always aware of the resources available to the families of children with disability (Lindsay, King, Klassen, Esses & Stachel, 2012). Also, immigrant parents may find it difficult to define and express their information needs and may instead wait for healthcare providers to provide guidance (Alsem et al., 2014). Immigrant parents would use disability services if they knew about them, but they may have not been told by service providers or healthcare professionals about the available services for their children with disability. Such findings highlight the importance of the clear communication between service providers, healthcare professionals and immigrant parents. Providing information through competent service providers and/or healthcare professionals to immigrant parents about the available services for their children with disability, the purposes of these services and the rationale for using these services through information sessions is important. Information should be provided in simple language or translated to the parents' first language if needed. It is vital for service providers to provide the right information to immigrant parents and encourage them to access the services.

Although not reported by the participants of the present study, knowing how to get in touch with the NDIS to access services for children diagnosed with a disability can be a challenge. About 1.5 million people from CALD communities have disabilities, but less than half of them have attended NDIS services (RCOA, 2019). One of the main steps to gaining access is that the immigrant parents need to know that the NDIS and disability services are available. General Practitioners (GPs) are often involved in assisting people in their application to become NDIS clients (RCOA, 2019). Such services are available to both immigrant and non-immigrant families. The central

role of GPs is to provide clinical information that forms part of the evidence of disability to support an NDIS access request. GPs have a role to help potential clients to gain a better understanding and connecting with the NDIS services (NDIS, 2019). GPs and healthcare professionals in Australia who are involved in the child's diagnosis and care are also responsible for educating immigrant parents about the NDIS and referring them to this service (NDIS, 2019). In everyday life, GPs are involved in taking care of immigrant children with disabilities and their families. This involves following up appointments, treatment and medication prescription, physical examination, pathology screening, catch up immunisation, further management and referrals as appropriate (RCOA, 2019). To access NDIS services, immigrant parents need to contact the NDIS team through the website to complete the access request form which is provided online and in English. They can also visit the local area coordinator, early childhood early intervention partner or contact the local NDIS office. Immigrant parents need to provide documents such as an Evidence of Disability Form to prove their eligibility for NDIS services (NDIS, 2019).

For immigrant parents who have not used online applications before, this is challenging, and being a non-English speaker compounds this. When immigrant parents' applications are approved and they are eligible to use the NDIS, the parents need to set up their NDIS care plan. The care plan depends on the child's type of disability and age (NDIS, 2019). For immigrant parents who are not aware of the services provided by NDIS, particularly if these services are different from those provided by the parents' country of origin, this process and the presumed knowledge poses significant challenges. This may be one reason why many parents in this study perceived the system as complex and difficult to navigate and were hesitant to attend the services.

In terms of appraisal support, immigrant parents reported not receiving enough feedback regarding their caretaking of their children with disability. They reported receiving sometimes conflicting information or not receiving feedback regarding some issues related to their children's disability. Such lack of appraisal support might confuse immigrant parents who are unsure if they are parenting their children with disability correctly.

Immigrant parent raising children with disability have different social support needs than immigrant parents without children with disability. For example, they may need support when they are going for a medical appointment, someone to rely on and look after the children when they have work or other responsibilities and, most importantly, they need to be supported by family and a friendship network who accepted children with disability. The current study found immigrant parents faced difficulties in getting the support they needed and experienced a lack of different types of social support.

6.5.3 Feeling embarrassed over children's behaviours

The quantitative findings showed that 'feeling embarrassed over your child's behaviour' was the item with the highest score in Exhaustion and Uncertainty subscale. Such findings concurred with Narayan's (2015) study in the US that reported immigrant parents feeling embarrassed due to their children's disruptive behaviour, particularly in social gatherings with families and friends. The embarrassment could be related to the parents' culture, which considers children's behaviour as reflective of the parenthood and discipline they experience (Ryan, 2010). Thus, parents feel embarrassed if their children are not well behaved.

In the present study, qualitative interviews confirmed that immigrant parents of children with disability often did not want to socialise with families or friends because of their worries of their children's disruptive behaviour. While parent interviewees did

not mention embarrassment, they expressed the fear that their extended families or friends might not accept their children's behaviour or might otherwise react adversely. Parents' worries could be related to the stigma attached to disabilities. Bradby et al. (2007) reported immigrant parents feeling ashamed of their children's mental health problems. In some cultures, disability is associated with stigma and a sense of shame (Koschorke et al., 2017). In the present study, although parents did not mention stigma, it could be one of the reasons that they avoided social gatherings. If this stigma is not adequately addressed, parents may continue to avoid accessing their social networks, healthcare and/or social services and may face further social isolation and exclusion.

6.5.4 Adapting to a new culture

The pressures of adapting to a new culture and settling in a new country added to the challenges of immigrant parents of children with disability. The values and culture that immigrants have from their country of origin may conflict with the values and culture of the host country. This was expressed by immigrant parents in the present study. These values were reflected in different areas, such as social norms and role expectations. Parents expressed difficulty in accepting certain values and norms, for example, enrolling a daughter with disability in a swimming class due to the mixed-gender swimming pool which was not acceptable in the parents' culture.

Parents also reported the different expectations of the new culture as a challenge. Most participants were of Arabian, Indian or Afghani backgrounds, all of which are characterised by a collectivistic culture (Maadad, 2007; Chadda & Deb, 2013; Triandis, 2015). A collectivistic culture emphasises family and work group goals above individual needs or desires (Chadda & Deb, 2013). Australian culture is characterised as an individualistic culture which emphasises personal achievement regardless of the expense of group goals, resulting in a strong sense of competition (Triandis, 2015). When immigrant parents from a collectivistic culture moved to Australia, facing the

new individualistic culture, language, religion and values presented challenges. The need to adapt to the new culture compounded their existing challenges of raising their children with disability. Adjusting to the new culture's values and morals, some of which conflicted with their cultural values and morals, were necessary to integrate into the new culture so they and their children could live comfortably. The majority of participants in the present study came from cultures where extended family members, neighbours and the whole community are supportive and share parenting responsibilities with parents. The challenges associated with the lack of a similarly cultural norm were raised by some participants. It appears that the relatives and extended family members had assimilated into Australian culture and acted as per the individualistic culture. The immigrant parents did not expect this to happen and felt unsupported.

6.5.5 Similarities and differences in parental challenges of immigrant parents taking care of children with disability and other parents

This study found common challenges faced by parents such as navigating the complexity of the healthcare and education system, language barriers and social isolation. Such challenges have been identified in previous studies in the US, the UK and Canada (Al-Azzam, 2011; Beatson, 2013; Ijalba, 2016; Khanlou et al., 2015; Kwon, 2016; Wang & Casillas, 2012; Zechella & Raval, 2016).

Compared to immigrant parents without children with disability, parent participants in the present study had extra responsibilities in organising and attending medical appointments for their children, managing their children's behavioural issues, navigating the system of special needs' school and, most importantly, handling their children's high dependence on them at all the times. Parents could not leave their children with disability at home alone or trust others to take of their children. Thus, many were home bound.

Immigrant parents raising children with disability shared some similar challenges with non-immigrant parents raising children with disability—social isolation, lack of social support, overwhelming responsibilities and insufficient understanding of available services are common in these two parent groups (Heather, Desmond & Maryalice, 2006; Murray, Maslany & Jeffery, 2006). For example, a study exploring caregiving challenges among Australian carers who provided care to a family member with disability showed that carers faced challenges such as social isolation, financial hardship, physical and health issues, and psychological problems (Edwards & Australian Institute of Family Studies, 2008). However, challenges such as language barriers and living in a new culture were not experienced by non-immigrant parents raising children with disability. Immigrant parents experience additional challenges alongside raising children with disability.

Around 1.5 million people (21.9%) from CALD communities have disabilities, yet only 600,000 people from CALD backgrounds have accessed the NDIS scheme, representing about 9% of all participants (RCOA, 2019). Immigrant parents recruited in the present study were those who could access NDIS services. There are immigrant parents who cannot access NDIS services and they may face different challenges.

In summary, parent participants in the present study faced various challenges in raising children with disability in a host country, including overwhelming responsibilities, embarrassment over their children's behaviours, and cultural and social challenges. Service providers need to understand these challenges so that they can attend to the needs of immigrant parents of children with disability.

6.6 Coping Strategies Used by Immigrant Parents of Children with Disability

The findings suggested that immigrant parents of children with disability have a moderate coping level as indicated by F-COPES scores. A moderate level of coping

means that parents used some purposeful coping strategies to manage their challenges (Lazarus & Folkman, 1984). The parent participants in the present study had lived in Australia for a relatively long period (6–10 years), but their level of coping was not high as indicated by F-COPES scores. Thomas and Sumathi's (2018) study examined the impact of immigration period on the coping of immigrants without children with disabilities, with immigrants recruited from Zambia, Zimbabwe, Uganda, China, the US and the UK. Their results suggested that four years and above was an adequate period for adaptation to a new culture. Living in the host country for longer time will give the immigrant parents more opportunity to learn more about the host country, develop new networks and integrate more in the community, thus better coping (Khanlou, Mustafa, et al., 2015). However, the parent participants in the present study appeared that they needed more time to integrate into Australian culture. The overwhelming challenges of raising children with disability might have an impact on their adaptation process. Thus, service providers need to provide equal services for all immigrant parents regardless of their immigration period. Also, providing services to lightning parents' caretaking responsibilities and facilitating coping such as respite care is recommended.

Immigrant parents in the current study used different coping strategies such as reframing, mobilising family to acquire help from others and seeking spiritual support. They considered these strategies as helpful and effective.

6.6.1 Problem-focused coping

Coping strategies such as reframing and mobilising family to acquire help from others were considered problem-focused coping (Lazarus & Folkman, 1984). Problem-focused coping refers to active efforts by individuals to manage stressful situations and alter a troubled person–environment relationship to modify or eliminate the sources of stress via individual behaviours (Lazarus & Folkman, 1984).

Reframing strategy was the most frequently used coping strategy by immigrant parents raising children with disability in the current study. Reframing was the highest scoring subscale in the F-COPES. Reframing is a positive coping strategy which refers to parents' ability to redefine stressful events to make them more positive and more manageable (Kliewer, Fearnow & Miller, 1996). The use of reframing to cope with the challenges of caregiving had also been highlighted in an Asian study conducted among family caregivers of persons with dementia in Singapore which was related to the caregivers' culture (Tay et al., 2016).

In the present study, the ability to use this coping strategy is likely reflective of the participants' educational (74.6% had high school education or above) and religious profile (92.6% had religious beliefs). Education level and religious beliefs may have positive influence on the ability of immigrant parents to use reframing as a positive coping strategy. More educated immigrant parents might view and experience events, ideas, concepts and emotions as positive learning experiences that aid in future decisions (Hashemi, Razavi, Sharif & Shahriari, 2007; Fischer, Ai, Aydin, Haslam & Frey, 2010). They might also be more resourceful in finding support for their children. Religious beliefs can shape parents' psychological perception of pain or disability as they create a mindset that enables them to relax and see the positive side of their challenges (Joshi, Kumari & Jain, 2008).

'Believing we can handle our own problems' was highest scoring item in the reframing subscale. This indicated that immigrant parents utilised this coping strategy more. The participants reported being optimistic and believing in themselves as strong enough to handle the challenges of raising their children with disability. They viewed the challenges in a more positive way (Al-Azzam, 2011). Parents who believe in themselves as able to handle the challenges perceive challenges as manageable and cope better.

‘Accepting that difficulties occur unexpectedly’ was the lowest scoring item in the reframing subscale. This means that immigrant parents did not accept that challenges occur unpredictably. They perceived the challenges as expected and predictable. The participants preferred to prepare themselves and have plans for potential challenges so they can react properly. The qualitative findings suggested that immigrant parents sought informational support and prepared themselves by putting plans in place to manage potential expected challenges. This proactive approach was considered a positive coping strategy (Guribye, Sandal & Oppedal, 2011). Proactive coping involves the collection of information, accumulation of resources and long-term strategic goal planning to adapt well and ensure quality of life (Guribye et al., 2011). Being proactive in managing potential challenges assisted the participants in coping.

Mobilising family to acquire and accept help was the second most commonly used coping strategy. This coping strategy described the family’s ability to seek community resources and accept help from others. It was considered positive problem-focused coping (Lazarus & Folkman, 1984). The highest rated item in this subscale was ‘Seeking professional counselling and help for family difficulties’. ‘Seeking information and advice from the family doctor’ was also highly rated by participants. Participants provided examples of seeking assistance from professionals, doctor and disability agencies. These findings differ from those of John et al.’s (2016) study that examined the support resources for immigrant parents raising children with disabilities in the US and found that immigrant parents perceived doctors, nurses and disability services as the least supporting resource (instead support from family members was regarded as vital and the priority). Immigrant parents in the current study found themselves in a situation where they did not receive support from extended family, friends and neighbours, and instead turned to professionals, doctors and disability agencies for support.

‘Seeking information and advice from persons in other families who have faced the same or similar problems’ was the lowest rated item in the coping subscale. This means that immigrant parents would prefer not to attend support groups where families with the similar situations meet to share their experiences raising children with disability. These findings differ from Lee and Park’s (2016) study that explored the experience of the Korean immigrant parents in the US. Their findings suggested that parents appreciated the opportunity to develop supportive relationships with other immigrant families raising children with disability. They regarded the support groups as providing them not only with information but also with encouragement, support, reassurance, optimism and hope (Lee & Park, 2016). Support from families facing a similar situation (such as via support groups) should be a helpful strategy for immigrant parents; however, immigrant parents in the present study did not appreciate such support.

Support groups held by the NDIS usually included immigrant parents from the same culture since they share the same language, values and norms. Immigrant parents not attending these support groups may be due to parents feeling shame at disclosing their children’s disability within their own community. Service providers pointed to this issue when they reported how difficult it was to introduce immigrant parents to other parents from same culture in a support group. Similarly, Al-Azzam’s (2011) study among Arab mothers of children with Attention Deficit Hyperactivity Disease living in the US similarly found that parents felt ashamed to disclose having children with disabilities and worried that they would bring shame to their family if they sought help from healthcare professionals.

6.6.2 Emotion-focused coping

Emotion-coping strategies were used by immigrant parents in the present study. Emotion-focused coping refers to strategies that attempt to reduce negative emotional

responses that occur due to exposure to stressors. It is aimed at positively managing the emotions associated with the situation, rather than changing the situation itself (Lazarus & Folkman, 1984).

The present study showed that seeking spiritual coping was frequently utilised by immigrant parents raising children with disability. 'Having faith in God' was the highest scoring item in the seeking spiritual subscale. The qualitative data confirmed that participants considered having faith in God and prayer as essential components in coping with challenges. They considered having faith a helpful coping strategy. Emotion-focused coping might not have a direct impact on resolving problems but serves other functions. For example, Pargament (1987) noted that religion might serve important functions in helping people understand and cope with life events by offering guidance, support and hope. Spilka, Shaver and Kirkpatrick (1985) regarded religion as providing a frame of reference for individuals to help them understand, predict and control events, and maintain self-esteem, thus allowing them to solve their problems. Religion represents a potentially significant element in the problem-solving process (Hathaway, 1988).

Seventy-two (53.7%) participants in the present study were Muslims and 38 (28.4%) were Christians. There was no significant difference in coping among people with different religions. Seeking spiritual support is different from having religious beliefs. Immigrant parents could seek spiritual support without having religious beliefs. Spirituality sometimes goes with a set of practices that may be reassuring and possibly healthy. Activities such as meditations, reflections and directions are good forms of exercise that make sense, independent of any religious justification (Thagard, 2016). Thagard's (2016) study highlighted the importance of spiritual support regardless of parents' religion. Immigrant parents in the current study mainly reported having faith in god as the most helpful spiritual support that assisted them to cope better. Immigrant

parents did not report using spiritual activities other than Faith in God. They also did not report the need of having other spiritual activities such as meditations, reflections and directions. They might be unaware of other spiritual activities or the effectiveness of such activities. Spiritual exercises such as meditations and reflections practised on a regular basis might be helpful for the immigrant parents (Thagard, 2016).

‘Passive appraisal’ was the least used strategy (Mean = 11.37, SD = 4.68) in the present study. Passive appraisal coping refers to feeling of helplessness to deal with the stressor and relying on others to resolve the stressful event or situation (Zeidner & Saklofske, 1996). The use of passive appraisal, a form of cognitive distraction such as ‘watching TV’ and ‘feeling that no matter what we do to prepare, we will have difficulty handling problems’ are noted as an emotion-focused coping strategy (Lazarus & Folkman, 1984). Passive appraisal is considered a negative coping strategy when it stifles family communication in regard to the new challenge, thus undermining the availability of support to parents. However, in some cases, such strategies may allow the individual to accept and minimise reaction to a difficult situation for short period of time, though the problems remain (Lazarus & Folkman, 1984). Participants in the present study preferred to be proactive and responsive to their challenges and to not ignore or avoid facing their problems.

6.6.3 Positive gains from parental experience

Positive gain is defined as the perceived benefits of raising a child, including growing as a person, learning new skills and becoming more determined to face challenges (MacMullin, Tint & Weiss, 2011). Participants in the current study reported positive gains from raising a child with disability in a host country. They reported being strong enough to stand up, learn new things and face challenges in a positive manner as positive gains. It appeared that living away from extended family and in an individualistic culture forced these parents to learn to depend on themselves and grow

stronger. Immigrant parents also reported that they recognised themselves as doing the best thing in nurturing their children with disability.

Participants found different meanings of life when they took care of their children with disability. Parents looked to life in a different way, believing that there was a reason for having a child with disability and spending the effort was worthwhile as they would be rewarded. Parents were also proud of their abilities to find new resources for their children, learn new skills and become more determined in facing everyday challenges in raising their children with disability in Australia.

Despite the difficulties, immigrant parents perceived gains from their challenges. The positive gains—new learning, new skills and different life perspectives—might contribute to the growth of the parents, which could help to enhance their resilience.

6.7 Level of Resilience and Factors Affecting Resilience

This study showed that immigrant parents had a reasonable level of resilience (Mean = 26.12, SD = 10.94; range = 4–40) in the CD-RISC 10. Immigrant parents seemed to have reasonable ability to bounce back to their normal life after facing challenges and had the capacity to manage stress and challenges (Min et al., 2013), but such capacity could be improved. Immigrant parents may have developed a variety of skills and resources during their lifetime, particularly throughout their immigration process, and may use these skills and resources more efficiently to manage their challenges after immigration.

‘Adapt to change’ was the highest scoring item in the CD-RISC 10. Participants perceived themselves as resilient since they could adapt to the changes that occurred in their daily life. The qualitative findings confirmed that immigrant parents were ready to face challenges as they trusted in their own abilities to solve problems. They reported having their own plans in place to manage challenges. Participants also reported being connected to social networks as a very helpful strategy for enhancing their resilience

and adapting to challenges. Immigrant parents were found to be actively seeking solutions to meet challenges. They also reported having English-language skills as a helpful factor for enhancing their resilience and adapting to changes. Having English-language skills enables parents to better communicate with others, navigate the healthcare and education system, and find more resources for their children, thus becoming more resilient.

Participants reported that being connected and supported by professionals and disability services (NDIS) made their lives easier and assisted them to be more resilient. Ozbay et al. (2007) reported social support received from healthcare professionals and disability service were reported as exceptionally important for enhancing individuals' resilience. Parents in the present study perceived social support received from professionals and disability services as helpful in building their self-confidence and resilience.

The quantitative findings showed that employment status was a factor associated with the immigrant parents' resilience level. Employed immigrant parents had a significantly higher level of resilience compared to unemployed and retired immigrant parents. In general, employed individuals have higher income, have greater wealth, live longer and healthier lives, have better physical and mental health (especially in terms of sense of belonging and self-worth), are more optimistic about the future, can communicate better and are more resourceful compared to unemployed individuals (Lutz & Samir, 2011; North West mental wellbeing survey, 2009). Thus, employed people have higher levels of resilience. In the present study, most participants were unemployed, and this is likely a reason for their relatively moderate resilience level.

6.8 Relationship among Challenges, Coping and Resilience

The present study suggests that immigrant parents facing a higher perceived level of challenges had lower coping and resilience levels, while those with better

coping and resilience levels perceived a lower level of challenges. These results support those of Shah, Collard and Morisset (2018). Participants in the current study faced daily challenges, but those who responded to the challenges directly and in timely manner, being proactive in managing their challenges, had plans in place for expected challenges, used available resources, and sought assistance from healthcare professionals and disability services felt less challenged and coped better. Levels of resilience and coping appear to directly impact perceived level of challenges. Therefore, improving immigrant parents' resilience and coping is crucial to lessening the perceived challenges they face.

Participants who utilised more coping strategies, such as reframing, seeking spiritual support, and acquiring help and accepting help from others, had significantly less perceived challenges and better coping. This was confirmed by the qualitative and quantitative findings. For example, participants who sought spiritual support through prayers and attending religious activities reported feeling less challenged in raising their children with disability. This supports Picardi et al.'s (2018) findings in Italy on the relationship between parental burden and coping resources and strategies (especially reframing and acquiring social support) among parents of children with autism.

Participants in the current study felt that an optimistic outlook had helped them to cope. The availability of a disability service that provided parents and children with required support plus financial support from the government and NDIS assisted parents in being more optimistic about the future of their child, allowed them to cope better and made them feel less challenged. Having religious beliefs and higher level of education may also enhance parents' coping and reduce perceived level of challenges.

The present study found that parents with a higher level resilience coped better and perceived less challenges, supporting the findings of Joling et al. (2016).

Individuals with high resilience have been found to respond positively to the caregiving

experience, to view this process as a positive gain and adapt to change more quickly, perceiving less challenges because of their higher social relations and resources (Senturk, Akyol & Kucukguclu, 2018). This was also found in the present study.

6.9 Perceived Barriers and Facilitators of Coping

6.9.1 Barriers

The findings of the present study suggest that service providers perceived various barriers negatively impacting social networks for immigrant parents, such as feeling ashamed and embarrassed at their children's behaviours, overwhelming responsibilities for immigrant parents and language barriers. Service providers perceived immigrant parents as feeling ashamed to have a child with disability. Service providers highlighted the fact that immigrant parents not only avoided disclosing their children's disability to their friends, neighbours and community, but also not disclosing this to their family doctor or healthcare professionals. Parent participants did not mention this. This is likely related to culture. In some cultures, disability is associated with stigma and a sense of shame (Koschorke et al., 2017). If this issue is not addressed, it can lead to parents experiencing social isolation and delays in receiving appropriate services and meeting the needs of their children with disability.

Immigrant parents reported overwhelming caretaking responsibilities as a challenge. Service providers agreed that immigrant parents face overwhelming responsibilities and regarded it as a barrier to their coping. Service providers perceived immigrant parents' lives as very busy and overloaded with responsibilities, including attending appointments in different governmental services and looking after their family plus their children with disabilities. Such findings concur with Khanlou et al.'s (2015) study which found that immigrant parents are often overloaded by their daily responsibilities and that this might delay their coping. Overwhelmed parents may not have enough time to look after themselves, solve their problems or seek more

community support, which will affect their coping. Such findings highlight the importance of disability services in providing social support to these parents, especially childcare services and respite care.

The study findings showed that both service providers and immigrant parents perceived language as a barrier hindering immigrant parents' coping. Language barrier made it difficult for new immigrant parents to access the healthcare and education systems, competently attend to children's needs and utilise available resources, thus influencing their ability to cope. These findings are supported by Su (2008) and Zechella and Raval's (2016) studies. Despite language difficulties, participants were very keen to seek support from professionals and disability services and considered this to be vital support for their coping. Given the fact that the participants in the current study were able to speak, read and understand basic English, the challenges are assumed to be duplicated for immigrant parents who could not speak English. Such findings highlight the importance of healthcare professionals and service providers being aware of the language barrier and inadequate knowledge about medical terms among immigrant parents.

Immigrant parents' culture was perceived by service providers as a barrier hindering their coping, but this was not mentioned by parents. Service providers perceived immigrant parents as unaware of their rights in the host country. This could be due to parents' previous experience in their country of origin or being a minority group in Australia and feeling scared to ask about their rights. Service providers considered the parents being aware of their rights and the services they are entitled to as important. The immigrant parents perceived service providers as having not provided this information. Further, language barriers made it difficult for them to access and comprehend this type of information themselves. Service providers reported that even when immigrant parents were aware of their rights, they were still hesitant to enquire

about services. This could be a reflection of parents' assumptions that healthcare and social support provided by the Government and disability services are privileges that can be withdrawn, rather than rights (Sandhu, Ibrahim & Chinn, 2017).

Immigrant parents need to be educated by service providers and healthcare professionals about their rights and available services. Healthcare professionals and services providers need to be sensitive to language barriers and cultural needs while interacting with immigrant parents. Culturally competent service providers could facilitate building of trusting relationship with immigrant parents, enabling parents to approach service providers when needed and not hesitate to access services. Also, using the interpreting services could lead to better communication with the community and could facilitate navigation of healthcare and education systems (Khanlou et al., 2015).

Immigrant parents in the current study also reported the language barrier and being living in a new culture as factors preventing them of getting better education or better employment. To break the language and culture barriers, immigrant parents could enrol themselves in English courses to learn the language of the host country. It also recommended to introduce programs for new immigrants offered by host country's government or by voluntary organisations (Koschorke et al., 2017). Engaging in community activities, creating new networks and learning the host country norms and values could help immigrant parents to integrate more in the host country's culture (Koschorke et al., 2017).

Service providers mentioned various perceived barriers to immigrant parents utilising available disability services, but this was not mentioned by parents. These included insufficient understanding of disability services and parents' culture. Insufficient understanding of available disability services among immigrant parents might occur because these parents have not been given enough information by service providers regarding the available disability services and importance of each service.

Parent participants highlighted the importance of being prepared and for healthcare professionals or service providers to provide them with the information they need to access services to which they are entitled. Lack of information about the services available and how to access them limited parents' ability to navigate the services, leading to inability to attend to their children's needs or provide appropriate care. More sharing of information and experiences between service providers and immigrant parents will facilitate parents' understanding of disability services and encourage them to attend these services.

6.9.2 Facilitators

Service providers perceived various facilitators impacted immigrant parents' coping positively, such as services with competent staff, availability of social support and steps necessary to take control of situations. Availability of disability services including competent service providers (staff) was perceived as a significant facilitator for enabling immigrant parents' coping. Availability of service providers specialised in disabilities who can provide immigrant families raising children with disability the required information, equipment and instruments would be very helpful for parents (COAG, 2017).

Parents shared this perception, reporting that being supported by appropriate disability services such as NDIS and receiving support from competent service providers made a huge positive difference in their lives. Social support provided to immigrant parents by service providers should include not only information support but also encouragement, support, reassurance, optimism and hope (Lee & Park, 2016). Parents in the present study appreciated the NDIS services they had received and believed that they would not be able to continue raising their children with disability without NDIS services.

Although parents' appreciation may reflect the quality of the healthcare and disability services provided to them, it is important to consider that these participants came from countries with either very different services or no public welfare system. Varied experiences of healthcare services in their countries of origin may have influenced their expectations of and the way they experienced Australian disability services.

Service providers concurred with immigrant parents that those who took control over their challenges, tried to access to more resources and services, and used better problem-solving techniques had better coping. Service providers reported that immigrant parents who were willing to socialise more and connected with other communities had better self-confidence and, thus, better coping. Wang and Casillas's (2012) US study reported that immigrant parents raising children with disability who confronted their challenges by searching for knowledge related to their children's disability and looking for appropriate community resources had better coping. Immigrant parents who look for more community resources and have more problem-solving techniques might find more alternatives and the right information, including how to access to services provided by the host country, thus enabling them to cope better.

6.10 Summary of Findings

This study's findings are summarised by a conceptual framework shown in Figure

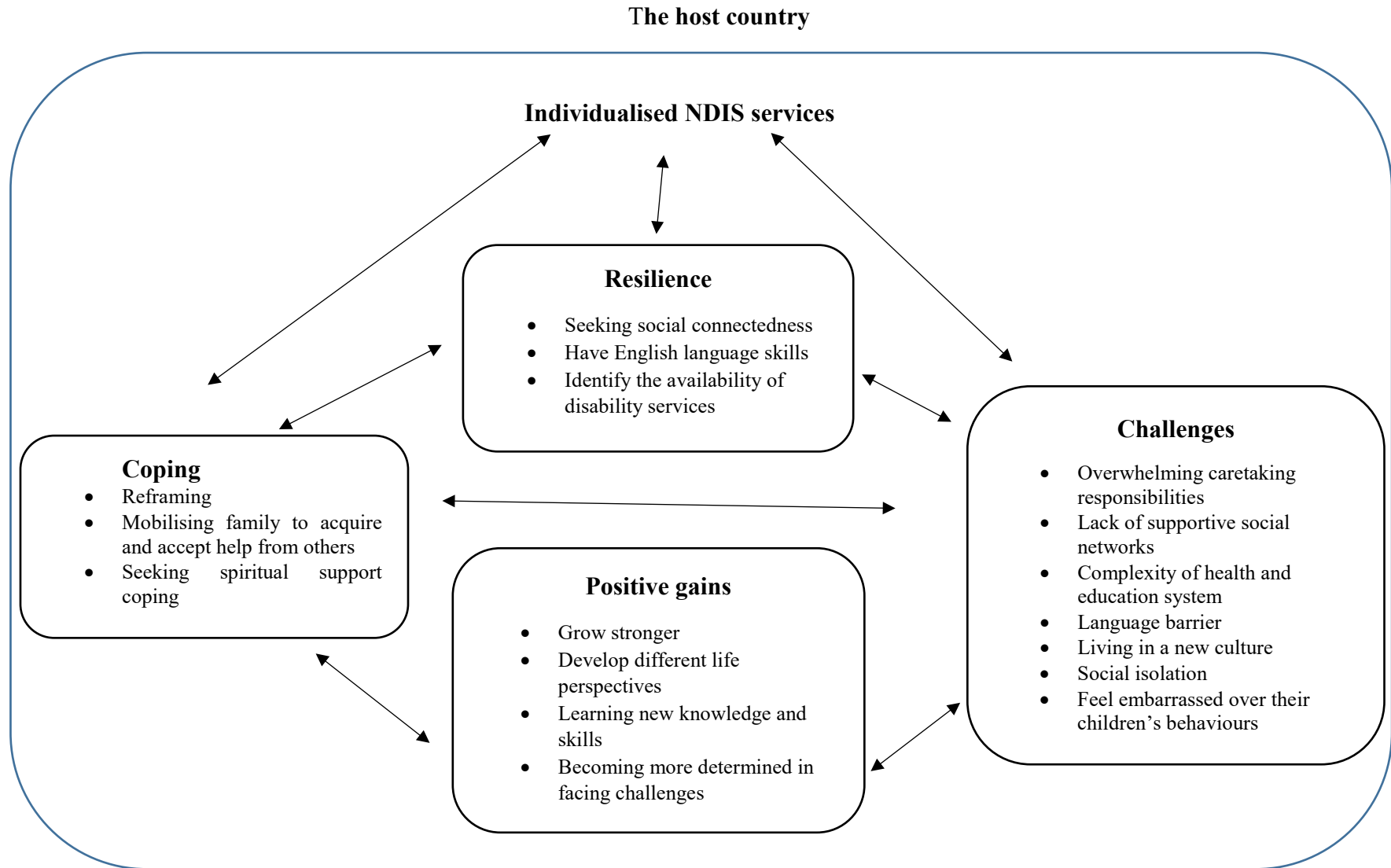


Figure 3. Conceptual framework of the study's findings.

As shown in Figure 3, immigrant parents of children with disability living in a host country face numerous and varying challenges. Bidirectional and interactive relationships were found among parental challenges, coping, resilience, positive gains and NDIS services. Parents' coping, resilience and positive gains have an impact on their perceived challenges. Immigrant parents who have better coping strategies and better resilience have less perceived challenges. Of the various coping strategies, reframing, acquiring social support, and seeking spiritual support are regarded as helpful and most frequently used by parents of children with disabilities. Future interventions for parents should focus on enhancing these strategies.

This framework concurred with study findings from Shah, Collard and Morisset (2018) and Picardi et al. (2018) on the relationship between parental perceived challenges, coping resources and strategies. In both studies, caregivers who reported high level of perceived challenges in caring for patients with chronic diseases and children with disabilities showed lower coping level and less using of coping resources, thus lower level of resilience (Shah, Collard and Morisset, 2018; Picardi et al., 2018).

The availability of appropriate disability services positively impacts parental challenges, coping and resilience. Immigrant parents who receive appropriate NDIS services for their children have better coping and resilience. Similarly, Ozbay et al. (2007) reported social support received from professionals and disability services as helpful in building individual's self-confidence, better coping and resilience.

Despite the challenges, parents have positive gains -grow stronger, develop different life perspectives, learn new knowledge and skills and become more determined in facing challenges. The positive gains help parents to overcome challenges and enhance their coping. Being an immigrant living away from extended family and in an individualistic culture, these parents learn to depend on themselves and grow stronger,

which could help to enhance their resilience. The concept of positive gains has not been mentioned in previous studies related to immigrant parents of children with disabilities. Though similar concept have been mentioned in studies related to dementia care and palliative care (Chan, 2010; Leow & Sally, 2016). Previous studies on immigrant parents of children with disabilities focused on burdens and challenges. It is important to focus on the positive side of caregiving. Future well-designed psychoeducation interventions should help to enhance parents' positive gains and resilience.

Immigrant parents have varying levels of challenges, coping and resilience, NDIS services need to be tailored for individual circumstances. The types and levels of parental challenges, coping and resilience may determine parents' individual NDIS service needs. A thorough assessment with individual care plan for parents and their child with disability is essential to enable the family receive the support that catered for their needs. An individualised service should focus not only in addressing the child's physical and psychosocial needs, but also the parents. Services providing to parents to enhance their coping, positive gains, and resilience are essential to help them carrying on their caregiving role. The focus of the individualised services should take into account of parents and children's immigration status. They need individualised services in adapting to the new culture, language, education, employment, social support and be connected to the new community. Service providers could work with parents on a one to one basis to help them manage their needs and supports.

The framework developed from the current study need further testing in future studies to confirm the relationship among the proposed components. The framework will be applicable in Australia and other host countries which may have similar characteristics and services like Australia. The service provider NDIS represents major service providers for people with disabilities in different countries.

6.11 Study Strengths

This study is the first in Australia to focus on examining the relationship between challenges, coping and resilience among immigrant parents raising children with disability. The study adopted a mixed methods design. This design assisted the researcher to gain an in-depth understanding of the experience of raising children with disability among immigrant parents. In Phase 1, data were collected from a large population ($n = 134$) and is generalisable to the larger population of immigrant parents raising children with disability in Australia and similar countries. In Phase 2, the researcher gained an in-depth understanding of immigrant parents' challenges, coping and resilience in raising their children with disability through interviews with parents and disability service providers. The understanding gained from these interviews strengthened the current study as it enabled the researcher to gain a holistic understand of the investigated phenomena from immigrant parents and service providers. The sample size of the second phase was sufficient to achieve data saturation to describe the phenomena of interest and address the research questions.

6.12 Study Limitations

This study has several limitations. Immigrant parents recruited in this study using convenience sampling, which might introduce researcher biases in recruiting the participants. Immigrant parents who are willing to participate in this study were recruited. This might increase the chance of bias. Immigrant parents recruited in this study were able to read, speak or understand basic English (Fifth Grade level). Immigrant parents who have difficulty in using English may have different challenges, coping and resilience which were not captured in this study. Further, this study recruited immigrant parents who were raising

children with disability regardless of the type of disability and did not distinguish between the challenges and coping among different types of disability and level of disability.

More than half of the participants were from Middle Eastern countries and shared the same culture and language, the generalisability of the findings are therefore somewhat limited. Immigrants were examined as one category in this study; however, immigrants are not a homogenous group. The participants were recruited from two cities in Australia, and immigrant parents in other states or cities may have different challenges and coping. People of ethnic and racial minorities and CALD groups have specific identities, and face different challenges, coping and resilience. This study did not delve into this. Most participants had resided in Australia for over six years. Immigrant parents with less years of residency may have different challenges, coping and resilience.

6.13 Implications for Practice and Policy Development

Service providers need to increase their awareness of multicultural and immigrant issues such as living in a new culture, lack of supportive networks (especially lack of family support), feeling stigmatised and being socially isolated. Service providers need to understand the uniqueness of the challenges faced by immigrant parents raising children with disability which make their experience more complicated than that of immigrant parents without children with disability or non-immigrant parents. Increased awareness will facilitate deeper understanding of the challenges and service needs of immigrant parents raising children with disability.

Service providers need to recognise that people from CALD backgrounds are not homogenous. They need to understand immigrant parents' culture, values and belief system so they can provide appropriate care. It is critical for healthcare professionals and service providers working with immigrant families from a different culture or ethnic group to

recognise the uniqueness of all people and avoid stereotyping or making assumptions based on a person's ethnicity, religion, culture or language. Assumptions obscure proper assessments and limit interventions and the development of trust (Lynch & Hanson, 2004). Service providers should avoid making assumptions by asking for clarification when needed, checking that what has been discussed is properly understood, and acknowledging limited understanding and asking for assistance (e.g., interpreting services) where necessary to increase understanding (Lynch & Hanson, 2004).

Developing cross-cultural competence among service providers is needed. Cultural competence is increasingly being used in relation to the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, race, ethnic background, religions and other diversity factors in a manner that recognises and values the worth of individuals, families and communities and protects and preserves the dignity of individuals (National Association of Social Workers, 2015).

According to Sue & Sue (2012), there are three key elements that are commonly identified in the development of cultural competence. The first is developing cultural awareness, including self-awareness about one's own culture. The second is acquiring knowledge about other cultures, may be achieved by interacting with people from other cultural backgrounds in both professional and personal life, talking with service providers and community organisations who work with culturally diverse people, researching, watching films or documentaries or reading about other cultures and cultural diversity, and participating in workshops and seminars. The third element is developing cross-cultural skills by establishing effective relationships with people from CALD backgrounds, reflecting on and learning from each interaction with people from different cultures to inform future practice, and identifying practices and systems that hinder cultural competency. These three elements should be included in cultural competency training.

Immigrant parents in the present study appreciated being supported by service providers who are culturally competent in providing care. Service providers need to have continuous professional development to enhance their cultural competency. Cultural competency has been incorporated in the pre-service training curriculum of many healthcare and social professionals' education. After entering the field, healthcare professionals and service providers need to be supported through ongoing professional development on cultural competency. Cultural competence training (CCT) is a training and education program provided by the Australian Government and some private institutions targeting service providers who deal with immigrant from CALD communities. CCT assists individuals and organisations to develop the skills and tools needed to foster, manage and contribute to diverse teams and inclusive practice. This program has been proven to significantly increase the cultural competence level of healthcare providers and is significantly associated with increased patient satisfaction (Govere, 2016). Healthcare professionals and service providers also need to take immigrant parents' coping mechanisms into consideration to evaluate their needs more effectively.

Service providers need to inform immigrant parents about their rights in seeking disability services. Education sessions regarding eligibility of different services would be helpful. Social and healthcare services may link immigrant parents to other parents in similar situations and from the same culture to exchange experiences regarding services available in the host country. Referring newly arrived immigrant parents raising children with disability to attend support groups was reported as very helpful as it increased their awareness of disability services (Khanlou et al., 2015). Service providers need to check with immigrant parents as to their readiness to participate in these groups prior to engaging them. They also need to ask parents for preference to engage with certain families to ensure they are comfortable. It would also be worthwhile to discuss the importance of attending

support groups between service providers and immigrant parents so they can understand each other's perspectives.

This study's findings suggested that language and communication are significant barriers for immigrant parents accessing healthcare system and services. The issue persists even when interpretation services are available because interpreters are interpreting the language, but parents still do not understand the healthcare and education systems. Immigrant parents and service providers believed that having a bilingual service provider who is a part of the social, health or education system and who can speak the parents' language is a great help for immigrant parents raising children with disability. This enhances service provider communication with parents, which aids in forming rapport and trust and giving parents a sense of understanding.

Information provided by healthcare professionals and service providers must be simple, clear and consistent; avoid jargons; and available in accessible formats, such as multiple languages, plain English and visual formats. The availability of easily understood information about disability and disability services in a person's preferred language, medium and format can have a positive impact on their use of disability services. Translated information must be culturally appropriate. Some people may not have sufficient experience in using information technology, which may limit their access to and engagement with information published online (RCOA, 2019). Developing marketing material (such as brochures, manuals and websites) targeting immigrant CALD communities, with attention to cultural diversity in visual representation and simple and easy languages, would be helpful. Information on disability services needs to clearly explain the meaning of 'disability' and the corresponding services provided for each form of disability (NDIS, 2019).

As immigrant parents with children with disability are using the healthcare system more than other immigrant parents, it is expected that they would face more challenges. It is recommended that the healthcare system, education system and disability service providers provide immigrant parents with adequate, appropriately written, culturally specific and congruent information about the healthcare system to assist in their transition to a new healthcare system. Service providers may consider targeting newly arrived immigrant parents with children with disability. Implementation of interventions such as invitation to community gatherings attended by other parents with children with disability and English-language classes are recommended to assist these parents to engage in the Australian community and improve their adaptation.

The findings highlighted the important role of disability agencies, the NDIS, service providers and healthcare professional in the process of supporting immigrant parents as they might not have extended family members to turn to. Increasing awareness among friends, neighbours and the whole community to provide support to these parents is suggested. The media will play a large role in increase awareness in this regard. Involvement of other services that provide caretaking of children with disability would also be helpful. Further, with the increasing involvement of fathers in childcare, disability services and service providers need to understand the experience and needs of immigrant fathers and support them in taking care of children with disability.

There is a need for cultural brokers, that is, expert mediators with interpreter skills, familiarity with the administrative aspects of relevant government programs, and the ability to work across both government and non-government organisations. The main role of these brokers is to provide culturally appropriate information and personalised guidance to parents as how to navigate the health and social welfare systems and access services (Miklavcic & LeBlanc, 2014). Implementing of the brokerage model for access to

community-based healthcare services in an urban setting among Aboriginal people in Australia has been widely successful (Dennis, Hasan, Jackson, Wilson & Zwar, 2014). Aboriginal participants reported that using brokers helped them to navigate the system and access healthcare system effectively, and that the healthcare professionals involved with the service were respectful of their needs (Dennis et al., 2014). This system could be adopted for immigrant parents raising children with disability.

Stigma over children's behaviours due to disability can be a major cause of social exclusion and hinder using disability services. Decreasing the stigma of disabilities may improve parental help-seeking behaviour. Two approaches can be used by service providers and policymakers to reduce stigma related to disabilities. Education is the first approach. Educational anti-stigma interventions can be implemented to present factual information about disability and stigma with the goal of correcting misinformation or contradicting negative attitudes and beliefs among community members (Hanisch et al., 2016). The media plays an important role in society, informing and educating people about disability and stigma. The second approach is encouraging connectedness (Hanisch et al., 2016). Service providers may encourage immigrant parents raising children with disability to interact positively with the public, describing their challenges and stories of success (Hanisch et al., 2016). These strategies are aimed at reducing public stigma but may also benefit self-stigma by creating a sense of empowerment and boosting self-esteem among parents raising children with disability.

Service providers need to understand and promote positive support among immigrant parents to change their mindset to overcome their feelings of embarrassment and shame. Evidence-based parent education programs that help parents of children with disability to manage their children's behaviour is recommended. Parent management training (PMT) program is an example of an effective program that helps parents raising

children with disability in managing children's disruptive behaviours. The effect of PMT on the disruptive behaviours in children with disabilities is significant and, consequently, decreases parental stigma over their children's behaviours (Skotarczak & Lee, 2015). The same training can be adopted among immigrant parents raising children with disability.

Service providers could also help to enhance parental coping and resilience by educating immigrant parents on how to cope and be resilient. Cognitive behaviour therapy-based interventions, parenting skills interventions program and mindfulness therapy are examples of interventions reported as enhancing coping and resilience (Reavley, Bassilios, Ryan, Schlichthorst & Nicholas, 2015). These could be implemented for immigrant parents with disabilities with outcomes evaluated. Service providers could focus on the strengths of immigrant parents' personalities to enhance coping and resilience.

This study's findings provide insights that will assist policymakers and service providers in formulating policy and services to meet the needs of immigrant parents of children with disability as they strive to decrease parental challenges and increase their coping and resilience. Policy and service systems may want to target unemployed newly arrived immigrant parents as they are more likely to experience higher levels of challenges and lower levels of coping skills and resilience. Government and policymakers should also encourage and facilitate enrolling immigrant parents in education and training courses to enable them to find suitable jobs and integrate with the host community.

6.14 Implications for Global Communities

Global communities need to improve data collection on prevalence of immigrants with disability and their carers. Accurate and updated data are essential to plan adequate and appropriate disability services and supports. Resettlement services for immigrants on arrival should be linked directly to disability services so that if any disability detected a

referral to a specialist for diagnosis will be made. By implementing this strategy, early support and intervention can be provided to immigrant families with children with disability.

Host countries' governments should develop strategies to ensure the full respect, protection and fulfilment of rights to which immigrant parents raising children with disability are entitled, such as promoting services in immigrant communities. Disability services should consider workplace diversity in their workforce strategy by recruiting team members from different cultural backgrounds to foster workforces that reflect and represent the cultural and linguistic diversity of the host country's population. Diverse teams are proven to be more innovative, creative and effective at decision-making (McKinsey & Company, 2018). Service providers have to ensure that there is culturally accessible information available and culturally competent processes and support in place for immigrant parents with children with disability.

6.15 Directions for Future Research

The framework developed in current study needs to be tested in future studies to provide more conclusive findings on the bidirectional relationships and interactions among challenges, coping, resilience, positive gains and service providers. Future research could apply random sampling to recruit participants to prevent research biases. Future research should include immigrant parents who are not English speakers and cannot understand, speak or read English as they might have different challenges compared to parents fluent in English. Examining parental challenges and coping strategies at different stages of children's development is recommended as this may impact parental challenges, coping and resilience. Additional research could address the coping strategies of other family members, such as siblings and extended family. Future studies should examine challenges, coping and

resilience among immigrant parents raising children with a specific type of disability or with different levels of severity as this could influence parents' experiences. Future research should recruit more parents without religious belief or practice to examine the impact of no religion status on parental challenges in caring for their children with disability.

Further studies could be conducted to explore the stigma that immigrant parents might encounter when raising children with disability to provide more conclusive findings in this area. This study identified positive gains as an important element in the coping process. Further research could focus on how to promote positive gains among immigrant parents raising children with disability.

Future research could use the stratified purposeful sampling for the qualitative phase, as this sampling method is able to capture the major variations and similarities of immigrant parents' challenges, coping and resilience in caring for their children with disabilities. Each of the strata would constitute a homogeneous sample (Patton, 2002).

Future research should have larger sample sizes with immigrant parents from more diverse backgrounds, such as those from the UK, New Zealand, China, Italy, and Vietnam. Such studies will add to the body of knowledge and increase awareness of their priorities and needs. Further research should focus on comparative study between coping strategies used by mothers versus those used by fathers. Future research that examines the caregiving experience of immigrant fathers is also recommended.

6.16 Conclusion

The challenges, coping and resilience of immigrant parents raising children with disability were examined in this study, including the perspectives of immigrant parents and service providers. Immigrant parents face the challenges of overwhelming caretaking

responsibilities, lack of supportive social networks, difficulty navigating the healthcare and education systems, language barriers, adapting to a new culture, social isolation and embarrassment over their children's behaviours.

Immigrant parents utilised problem-focused coping such as reframing and mobilising family to acquire and accept help from others. Due to the lack of extended family and community support, immigrant parents tended to seek assistance from healthcare professionals and disability service providers. Immigrant parents also utilised emotion-focused coping such as seeking spiritual support. Positive gains were an important part of parents' coping and resilience.

Immigrant parents and service providers shared the perception that the availability of disability services (NDIS) and competent service providers, and parents taking steps to establish control over a situation enhanced parental coping and resilience. While immigrant parents perceived spiritual support as one of the important coping strategies, service providers perceived social support provide by family, community and healthcare professionals as more important for parental coping.

References

- Al-Azzam, M. M. (2011). *Arab immigrant Muslim mothers' perceptions of children's Attention Deficit Hyperactivity Disorder (ADHD)* (Unpublished doctoral thesis). The University of Iowa, Iowa City, Iowa. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=109865717&site=ehost-live>
- Aloba, O., Olabisi, O., and Aloba, T. (2016). The 10-item Connor-Davidson resilience scale: factorial structure, reliability, validity, and correlates among student nurses in southwestern Nigeria. *J. Am. Psychiatric Nurses Association*. 22, 43–51. doi: 10.1177/1078390316629971
- Al-Rawashdeh, S., Lennie, T. & Chung, M. (2016). Psychometrics of the Zarit Burden Interview in caregivers of patients with heart failure. *Journal of Cardiovascular Nursing*. 31(6), E21–E28. <https://doi.org/10.1097/JCN.0000000000000348>
- Alsem, M. W., Ausems, F., Verhoef, M., Jongmans, M. J., Meily-Visser, J. M. A. & Ketelaar, M. (2017). Information seeking by parents of children with physical disabilities: an exploratory qualitative study. *Research In Developmental Disabilities*, 60, 125–134.
- Alsem, M. W., Siebes, R. C., Gorter, J. W., Jongmans, M. J., Nijhuis, B. G. J. & Ketelaar, M. (2014). Assessment of family needs in children with physical disabilities: Development of a family needs inventory. *Child: Care Health and Development*, 40(4), 498–506.

- Alvarado, M. I. (2004). Mucho camino: the experiences of two undocumented Mexican mothers participating in their child's early intervention program. *American Journal of Occupational Therapy*, 58(5), 521-530.
- American Psychological Association. (2014). *Resilience and recovery after war: Refugee children and families in the United States*. Washington, DC: Author. Retrieved from <https://www.apa.org/pubs/info/reports/refugees>
- Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research: Looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research and Policy Studies*, 5(2), 272–281.
- Aratangy, T. & Zerger, S. (2014). Mixed methods designs. *CRICH Survey Research Unit*. Retrieved from file:///C:/Users/c3267287/Downloads/SRU_MethodologyBits_2014_4_y14m09d15
- Attum, Basem, Waheed, Abdul & Shamoon, Zafar. (2020). *Cultural competence in the care of Muslim patients and their families*. StatPearls Publishing.
- Australian Bureau of Statistics. (2017). *Census of Population and Housing: Australia Revealed, 2016* (No. 2024.0). Canberra, ACT: Author. Retrieved from <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/2024.0Main%20Features22016>
- Australian Bureau of Statistics. (2019). *Australian Demographic Statistics, Jun 2019* (No. 3101.0). Canberra, ACT: Author. Retrieved from <https://www.abs.gov.au/Ausstats/abs@.nsf/7d12b0f6763c78caca257061001cc588/fa9c11f1913bdafcca25765100098359!OpenDocument>
- Australian Government. (2017). *Fact Sheet: 2017-18 Migration programme planning levels: Migration Programme planning levels*. Retrieved from

<https://www.homeaffairs.gov.au/research-and-stats/files/report-migration-program-2017-18.pdf>

Australian Human Rights Commission (2003). Ismae Report: National consultations on eliminating prejudice against Arab and Muslim Australians: Appendices. Retrieved from <https://www.humanrights.gov.au/our-work/race-discrimination/projects/isma-listen-national-consultations-eliminating-prejudice>

Australian Institute of Health and Welfare. (2017). *Autism in Australia*. Retrieved from <https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism>

Avasthi, A., Ghosh, A., Sarkar, S. & Grover, S. (2013). Ethics in medical research: General principles with special reference to psychiatry research. *Indian Journal of Psychiatry*, 55(1), 86–91. <https://doi.org/10.4103/0019-5545.105525>

Beatson, J. E. (2013). Supporting refugee Somali Bantu mothers with children with disabilities. *Pediatric Nursing*, 39(3), 142–145.

Blanche, E. I., Diaz, J., Barretto, T., & Cermak, S. A. (2015). Caregiving experiences of Latino Families with Children with Autism Spectrum Disorder. *American Journal of Occupational Therapy*, 69(5), p1-p11. <http://dx.doi.org/10.5014/ajot.2015.017848>

Bradby, H., Varyani, M., Oglethorpe, R., Raine, W., White, I. & Helen, M. (2007). British Asian families and the use of child and adolescent mental health services: A qualitative study of a hard to reach group. *Social Science & Medicine*, 65(12), 2413–2424. <https://dx.doi.org/10.1016/j.socscimed.2007.07.025>

Bradshaw, C., Atkinson, S. & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4. <https://doi.org/10.1177/2333393617742282>

- Breitkreuz, R., Wunderli, L., Savage, A. & McConnell, D. (2014). Rethinking resilience in families of children with disabilities: A socioecological approach. *Community, Work & Family*, 17(3), 346–365. <https://doi.org/10.1080/13668803.2014.893228>
- Brown SL, Nesse RM, Vinokur AD, Smith DM. 2003. Providing social support may be more beneficial than receiving it: Results from a prospective study of mortality. *Psychological Science*. 14(4): 320–327. [PubMed: 12807404]
- Calculator.net. 2108. Sample size calculator. Retrieved from <https://www.calculator.net/sample-size-calculator.html?type%20=%201&cl%20=%2095&ci%20=%205&pp%20=%2050&ps%20=%20200&x%20=%2053&y%20=%2018>
- Chadda, R. K. & Deb, K. S. (2013). Indian family systems, collectivistic society and psychotherapy. *Indian Journal of Psychiatry*, 55(6), 299–309. <https://doi.org/10.4103/0019-5545.105555>
- Chan, SW. (2010). Family caregiving in dementia: the Asian perspective in a global problem. *Dementia Geriatric Cognitive Disorders*, 30(6):469-78.
- Chan, SW. (2011). Global perspective of burden of family caregivers for persons with schizophrenia. *Archives of Psychiatric Nursing*, 25, 339-349.
- Choy, L. T. (2014). The strengths and weaknesses of research methodology: Comparison and complimentary between qualitative and quantitative approaches. *IOSR Journal of Humanities and Social Science*, 19(4), 99–104.
- Chui, WY & Chan, SW. (2007). Stress and coping of Hong Kong Chinese family members during a critical illness. *Journal of Clinical Nursing*, 16(2):372-81.

- COAG. (2017). *National Disability Insurance Scheme: COAG Disability Reform Council quarterly report*. Retrieved from <https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2018-19>
- Compas, B. E., Malcarne, V. L., & Fondacaro, K. M. (1988). Coping with stressful events in older children and young adolescents. *Journal of Consulting and Clinical Psychology*, 56(3), 405–411. <https://doi.org/10.1037/0022-006X.56.3.405>
- Connor, K. & Davidson, J. (2003). Development of a new resilience scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety*, 18(2), 76–82.
- Council of Australian Governments (COAG). (2017, June). National Disability Insurance Scheme: *COAG Disability Reform Council Quarterly Report*. Retrieved from <https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2016-17>
- Creswell, J. W. (2009). *Research design: Qualitative and quantitative approaches* (3rd ed.). London: SAGE Publication.
- Creswell, J. W. (2013a). *Research design: Qualitative, quantitative, and mixed methods approaches*. SAGE publications.
- Creswell, J. W. (2013b). Steps in conducting a scholarly mixed methods study. *DBER Speaker Series*.
- Creswell, J. W. & Plano-Clark, V. L. (2007). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage.
- Croot, E., Grant, G., Mathers, N. & Cooper, C. (2012). Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability & Rehabilitation*, 34(18), 1540–1549. <https://doi.org/10.3109/09638288.2011.650310>

- Dancygier, R. M., & Laitin, D. D. (2014). *Immigration into Europe: Economic discrimination, violence, and public policy*. *Annual Review of Political Science*, 17, 43-64.
- Decoteau, C. L. (2017). The "Western disease": Autism and Somali parents' embodied health movements. *Social Science and Medicine*, 177, 169-176.
- Dennis, S., Iqbal, H., Pulver, L. J., Wilson, I. & Zwar, N. (2014). Experiences and views of a brokerage model for primary care for Aboriginal people. *Australian Health Review*, 39(1), 26–32. <https://doi.org/10.1071/AH13205>
- Denzin, N. K. & Lincoln, Y. S. (2005). *The SAGE book of qualitative research* (3rd ed.). CA: SAGE Publications.
- disaster survivors. Retrieved from www.pap.org.ph/includes/view/default/uploads/pjp.../PJP1502_Final_2Docena.pdf
- Docena, P. (2015). Adaptive coping, resilience, and absence of anxiety among displaced
- Drinkwater, S. (2017). *Why does unemployment differ for immigrants?* IZA World of Labor. doi:10.15185/izawol.376
- Edwards, B. & Australian Institute of Family Studies. (2008). The nature and impact of caring for family members with a disability in Australia. Melbourne, Vic : Australian Institute of Family Studies, <http://www.aifs.gov.au/institute/pubs/resreport16/main.html>
- Eiraldi, R. B., Mazzuca, L. B., Clarke, A. T. & Power, T. J. (2006). Service utilization among ethnic minority children with ADHD: A model of help-seeking behavior. *Administration and Policy in Mental Health and Mental Health Services Research*, 33(5), 607–622.

- Esperón, J. M. T. (2017). Quantitative research in nursing science. *Escola Anna Nery*, 21(1). <https://dx.doi.org/10.5935/1414-8145.20170027>
- Fellin, M., King, G., Esses, V., Lindsay, S. & Klassen, A. (2013). Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability. *International Journal of Migration, Health, and Social Care*, 9(3), 135–145.
- Filipič Sterle, M., Vervoort, T. & Verhofstadt, L. L. (2018). Social support, adjustment, and psychological distress of help-seeking expatriates. *Psychologica Belgica*, 58(1), 297–317. doi:10.5334/pb.464
- Fischer, P., Ai, A. L., Aydin, N., Haslam, S. A. & Frey, D. (2010). The relationship between religious identity and preferred coping strategies: An examination of the relative importance of interpersonal and intrapersonal coping in Muslim and Christian faiths. *Review of General Psychology*, 14(4), 365–381.
- Flores, L. (2012). *Psychoeducational needs and concerns of immigrant Mexican parents of a child with Autism*. (Order No. 3539987). Available from ProQuest Dissertations & Theses A&I. (1095666024). Retrieved from <http://ezproxy.uws.edu.au/login?url=https://search-proquest-com.ezproxy.uws.edu.au/docview/1095666024?accountid=36155>
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine*, 45(8), 1207–1221. [https://doi.org/10.1016/S0277-9536\(97\)00040-3](https://doi.org/10.1016/S0277-9536(97)00040-3)
- Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2017). "It was like walking without knowing where I was going": A qualitative study of autism in a UK Somali migrant community. *Journal of Autism and Developmental Disorders*, 47(2), 305-315.

- Gallagher, Rappaport, Benedict & Lovett. (1985). *Reliability of selected interview and self-report measures with family caregivers*. Paper presented at the 38th Annual Scientific Meeting of the Gerontological Society of America New Orleans.
- Gallagher, S., Phillips, A.C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, 33, 1129-1136
- Chan, S. (2010). Family caregiving in dementia: The Asian perspective of a global problem. *Dementia and Geriatric Cognitive Disorders*, 30, 469-478
- Goins, R. T., Gregg, J. J., & Fiske, A. (2013). Psychometric properties of the Connor-Davidson Resilience Scale with older American Indians: The Native Elder Care Study. *Research on Aging*, 35(2), 123-143. <https://doi.org/10.1177/0164027511431989>
- Govere, Linda. (2016). How effective is cultural competence training of healthcare providers on improving patient satisfaction of minority groups? A systematic review of literature. *Worldviews on Evidence-Based Nursing*, 13(6), 402–410.
- Grandpierre, V., Milloy, V., Sikora, L., Fitzpatrick, E., Thomas, R., & Potter, B. (2018). Barriers and facilitators to cultural competence in rehabilitation services: a scoping review. *BMC Health Services Research*, 18(23), 18:23.
- Graneheim, U. H. & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112.
- Greenwood, N., Habibi, R., Smith, R. & Manthorpe, J. (2014). Barriers to access and minority ethnic carers' satisfaction with services in the community. *Health and Social Care*, 23, 64–78. <https://doi.org/10.1111/hsc.12116>

- Gregoire, J. (2011). An analysis of Haitian parents' perceptions of their children with disabilities. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 71(8-A), 2845.
- Greiner, K. A., Friedman, D. B., Adams, S. A., Gwede, C. K., Cupertino, P., Engelman, K. K. Hébert, J. R. (2014). Effective recruitment strategies and community-based participatory research: Community networks program centers' recruitment in cancer prevention studies. *Cancer Epidemiology, Biomarkers & Prevention*, 23(3).
<https://doi.org/10.1158/1055-9965.EPI-13-0760>
- Guba, E. & Lincoln, Y. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed.) (pp. 191–215). Thousand Oaks, CA: Sage.
- Guribye, E., Sandal, G. M. & Oppedal, B. (2011). Communal proactive coping strategies among Tamil refugees in Norway: A case study in a naturalistic setting. *International Journal of Mental Health Systems*, 5. <https://doi.org/10.1186/1752-4458-5-9>
- Hanisch, S. E., Twomey, C. D., Szeto, A. C. H., Birner, U. W., Nowak, D. & Sabariego, C. (2016). The effectiveness of interventions targeting the stigma of mental illness at the workplace: A systematic review. *BMC Psychiatry*, 16(1). doi:10.1186/s12888-015-0706-4
- Hashemi, F., Razavi, S., Sharif, F. & Shahriari, M. M. (2007). Coping strategies used by parents of children with cancer in Shiraz, Southern Iran. *Iranian Red Crescent Medical Journal*, 9(3), 124–128.
- Hassani, P., Abbasi, P., Zagheri Tafreshi, M., Zayeri, F. & Ziapour, A. (2018). Persian version of family crisis oriented personal evaluation scales: Psychometric

- properties. *International Journal of Pediatrics*, 6(1), 6919–6930.
- <https://doi.org/10.22038/ijp.2017.27746.2402>
- Hathaway, William. (1988). Religion and the problem-solving process: Three styles of coping. *Journal for the Scientific Study of Religion*, 27(1), 90–104.
- Heather, K., Desmond, R. & Maryalice, N. (2006). Child outcomes and family characteristics 1 year after severe inflicted or noninflicted Traumatic Brain Injury. *Pediatrics*, 117(2), 317–324.
- Hebert, R., Bravo, G. & Preville, M. (2000). Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal of Aging*, 19, 494–507.
- Heer, K., Larkin, M., & Rose, J. (2015). The experiences of British South Asian carers caring for a child with developmental disabilities in the UK. *Tizard Learning Disability Review*, 20(4), 228-238. <http://dx.doi.org/10.1108/TLDR-12-2014-0044>
- Honey, E., Hastings, R. & McConachie, H. (2005). Use of the Questionnaire on Resources and Stress (QRS–F) with parents of young children with autism. *AGE Publications and The National Autistic Society*, 9(3), 243–252.
- Hopia, H., Latvala, E., & Liimatainen, L. (2016). Reviewing the methodology of an integrative review. *Scandinavian journal of caring sciences*, 30(4), 662-669. <http://dx.doi.org/10.1111/scs.12327>
- Houser, J. (2011). *Nursing research: Reading, using, and creating evidence* (2nd ed.). Jones and Bartlett Publishers, Inc, Sudbury, United States
- Hurtado-de-Mendoza, A., Gonzales, F., Serrano, A., & Kaltman, S. (2014). Social Isolation and Perceived Barriers to Establishing Social Networks Among Latina Immigrants. *American Journal of Community Psychology*. <https://doi.org/10.1007/s10464-013-9619-x>St

- IBM Corp. (2016). IBM SPSS Statistics for Windows (Version 24.0) [Computer software]. Armonk, NY: IBM Corp.
- Ijalba, E. (2016). Hispanic immigrant mothers of young children with autism spectrum disorders: How do they understand and cope with autism? *American Journal of Speech-Language Pathology*, 25(2), 200–213.
http://dx.doi.org/10.1044/2015_AJSLP-13-0017
- Javalkar, K., Rak, E., Phillips, A., Haberman, C., Ferris, M. & Tilburg, M. V. (2017). Predictors of caregiver burden among mothers of children with chronic conditions. *Children*, 4(9). <https://doi.org/10.3390/children4050039>
- Jegatheesan, B., Fowler, S. & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability & Society*, 25(7), 797–811. <https://dx.doi.org/10.1080/09687599.2010.520894>
- Jesson, J. (2001). Cross-sectional studies in prescribing research. *Journal of Clinical Pharmacy and Therapeutics*, 26, 397–403.
- Joanna Briggs Institute. (2014). *Joanna Briggs Institute Reviewers' Manual* (2014 ed.). The University of Adelaide/South Australia: The Joanna Briggs Institute.
- John, A., Bower, K. & McCullough, S. (2016). Indian immigrant parents of children with developmental disabilities: Stressors and support systems. *Early Child Development and Care*, 186(10), 1594–1603. <http://dx.doi.org/10.1080/03004430.2015.1116297>
- Joling, K. J., Windle, G., Dries, R-M., Meiland, F., van Hout, H. P. J., MacNeil Vroomen, J., ... Woods, R. (2016). Factors of resilience in informal caregivers of people with dementia from integrative international data-analysis. *Dementia and Geriatric Cognitive Disorders*, 42(3-4), 198- 214. <https://doi.org/10.1159/000449131>
- Joshi, S., Kumari, S. & Jain, M. (2008). Religious belief and its relation to psychological well-being. *Journal of the Indian Academy of Applied Psychology*, 34(2), 345–354.

- Kabir, S. M. (2016). Methods of data collection. In book: Basic Guidelines for Research: An Introductory Approach for All Disciplines (pp.201-275), First edition, Book Zone Publication, Chittagong-4203, Bangladesh
- Kaiser Family Foundation. (2019). *Health coverage of immigrants* [Fact sheet]. Retrieved from <https://www.kff.org/disparities-policy/fact-sheet/health-coverage-of-immigrants/>
- Khanlou, N., Haque, N., Sheehan, S. & Jones, G. (2015). 'It is an issue of not knowing where to go': Service providers' perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities. *Journal of Immigrant and Minority Health*, 17(6), 1840–1847.
<http://dx.doi.org/10.1007/s10903-014-0122-8>
- Khanlou, N., Mustafa, N., Vazquez, L. M., Haque, N., & Yoshida, K. (2015). Stressors and barriers to services for immigrant fathers raising children with developmental disabilities. *International Journal of Mental Health and Addiction*, 13(6), 659-674.
- Kivunja, C. and Kuyini, A. (2017). Understanding and Applying Research Paradigms in Educational Contexts. *International Journal of Higher Education*, 6(5), p.26.
- Kliewer, W., Fearnow, M. D., & Miller, P. A. (1996). Coping socialization in middle childhood: Tests of maternal and paternal influences. *Child Development*, 67(5), 2339–2357. <https://doi.org/10.2307/1131627>
- Klocker, N., Trenerry, B., & Webster, K. (2011). How does freedom of religion and belief affect health and wellbeing?. *Victorian Health Promotion Foundation (VicHealth), Carlton, Australia.*
- Koschorke, M., Padmavati, R., Kumar, S., Cohen, A., Weiss, H., Chatterjee, S., Pereira, J., Naik, S., John, S., Dabholkar, H., Balaji, M., Chavan, A., Varghese, M., Thara, R., Patel, V., & Thornicroft, G. (2017). Experiences of stigma and discrimination faced

- by family caregivers of people with schizophrenia in India. *Social Science & Medicine*, 178: 66–77. doi: 10.1016/j.socscimed.2017.01.061.
- Kwon, J. H. (2016). What are the experiences of South Korean immigrant parents who have a child with autism spectrum disorder. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 76(11-B(E)).
- Lai, Y., & Ishiyama, F. (2004). Involvement of immigrant Chinese Canadian mothers of children with disabilities. *Exceptional Children*, 71(1), 97-108.
- Larsen, G. (2013). Family migration to Australia. *Parliamentary Library Research Paper, Series 2013–2014*. Parliament of Australia, Department of Parliamentary Services. Retrieved from https://parlinfo.aph.gov.au/parlInfo/download/library/prspub/2931915/upload_binary/2931915.pdf;fileType=application/pdf
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal and coping.
- Lee, Y.-J. & Park, H. J. (2016). Becoming a parent of a child with special needs: Perspectives from Korean mothers living in the United States. *International Journal of Disability, Development and Education*, 63(6), 593–607. <http://dx.doi.org/10.1080/1034912X.2016.1154139>
- Leow, M. Q. H. & Chan, S. W. C. (2017). The challenges, emotions, coping, and gains of family caregivers caring for patients with advanced cancer in Singapore: A qualitative study. *Cancer Nursing*, 40(1), 22–30.
- Levin, K. A. (2006). Study design III: Cross-sectional studies. *Evidence-Based Dentistry*, 7(1), 24–25.
- Lincoln, Y. & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: SAGE Publications, Inc.

- Lindsay, S., King, G., Klassen, A. F., Esses, V. & Stachel, M. (2012). Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation*, 34(23), 2000–2017.
- Luong, J., Yoder, M. K. & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *The Journal of School Nursing*, 25(3), 222–229. <https://doi.org/10.1177/1059840509334365>
- Lustig, D. C. (2002). Family coping in families with a child with a disability. *Education & Training in Mental Retardation & Developmental Disabilities*, 37(1), 14–22.
- Luther, E. H., Canham, D. L. & Young Cureton, V. (2005). Coping and social support for parents of children with autism. [Comparative Study]. *The Journal of School Nursing*, 21(1), 40–47. <https://doi.org/10.1177/10598405050210010901>
- Lutz, W. & Samir, K. C. (2011). Global human capital: Integrating education and population. *Science*, 333(6042): 587–592.
- Lynch, E. & Hanson, M. (Eds.). (2004). *Developing cross-cultural competence: A guide for working with children and their families* (2nd ed). Paul H. Brookes Publishing.
- Maadad, N. (2007). *Adaptation of Arab immigrants to Australia: Psychological, social, cultural and educational aspects* (Unpublished doctoral thesis). The University of Adelaide, Adelaide. Retrieved from <http://hdl.handle.net/2440/70149>
- Macedo, E. C., da Silva, L. R., Paiva, M. S. & Ramos, M. N. P. (2015). Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. *Rev. Latino-Am. Enfermagem*, 23(4), 769–777.
- MacMullin, J., Tint, A. & Weiss, J. (2011). Brief report: Professional support and positive gain for mothers of children with ASD. *Journal on Developmental Disabilities*, 17(2), 60–63.

- Martinez, O. (2005). *Experiences and coping strategies used by Mexican immigrant women in a California border town*. (Order No. 3193351). Available from ProQuest Dissertations & Theses A&I. (305356855). Retrieved from <http://ezproxy.uws.edu.au/login?url=https://search-proquest-com.ezproxy.uws.edu.au/docview/305356855?accountid=36155>
- McConnell, D., Savage, A. & Breitzkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, 35(4). <https://doi.org/10.1016/j.ridd.2014.01.015>
- McCubbin, H. I., Olson, D. H. & Larsen, A. S. (1991). *Family crisis orientated personal evaluation scales [F COPEs] (1987, 1991)*.
- McKinsey & Company. (2018, January). *Delivering through diversity*. Retrieved from https://www.efm-berlinale.de/media/pdf_word/efm/68_efm/microsites/horizon/diversity-report.pdf
- Migiro, S. & Magangi, B. (2011). Mixed methods: A review of literature and the future of the new research paradigm. *African Journal of Business Management*, 5(10). <https://doi.org/10.5897/AJBM09.082>
- Miglietta, A. & Tartaglia, S. (2009). The influence of length of stay, linguistic competence, and media exposure in immigrants' adaptation. *Cross-Cultural Research*, 43(1), 46–61. <https://doi.org/10.1177/1069397108326289>
- Migration Policy Institute, 2019. *Migration data hub*. Retrieved from <https://www.migrationpolicy.org/programs/migration-data-hub>
- Miklavcic, A., & Leblanc, M.N. (2014). *Culture Brokers, Clinically Applied Ethnography, and Cultural Mediation*, New York: Springer.

- Min, J. A., Yoon, S., Lee, C. U., Chae, J. H., Lee, C., Song, K.-Y. & Kim, T.-S. (2013). Psychological resilience contributes to low emotional distress in cancer patients. *Supportive Care in Cancer*, 21(9), 2469–2476. doi:10.1007/s00520-013-1807-6
- Moawad, G. E. N. A. (2012). Coping strategies of mothers having children with special needs. *Journal of Biology, Agriculture and Healthcare*, 2(8), 77-84.
- Multicultural Disability Advocacy Association. (2002). *Multicultural Disability Advocacy Association of NSW Annual Report 2007-2008 Summary*
- Murray, H., Maslany, G. & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury*, 20(6), 575–585.
- Mynarska, Monika, Riederer, Bernhard, Jaschinski, Ina, Krivanek, Desiree, Neyer, Gerda and Oláh, Livia. (2015). *Vulnerability of families with children: Major risks, future challenges and policy recommendations*. Retrieved from <http://www.familiesandsocieties.eu/wp-content/uploads/2015/11/WP49MynarskaEtAl2015.pdf>
- Narayan, N. (2015). Interplay between cultural beliefs and attitudes in raising a child with intellectual disability-an asian indian study. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 75(11-A(E)), No Pagination Specified.
- National Association of Social Workers. (2015). *NASW standards for cultural competence in social work practice*. Retrieved from <https://www.socialworkers.org/LinkClick.aspx?fileticket=PonPTDEBrn4%3D&portalid=0>
- National Commission of Audit. (2019). *Unemployment benefits and the minimum wage*. Australian Government. Retrieved from <https://www.ncoa.gov.au/report/appendix-volume-1/9-11-unemployment-benefits-minimum-wage>

National Disability Insurance Scheme. (2019, 25 January). *NDIS plans* [Media release].

Retrieved from <https://www.ndis.gov.au/news/1276-ndis-plans>

National Health and Medical Research Council. (2015). *National statement on ethical conduct in human research*. National Health and Medical Research Council
Canberra.

National Health Interview Survey. (2014). National Health Interview Survey 2014.

Retrieved from. https://www.cdc.gov/nchs/data/nhis/nhis_english.pdf

Neale, A., Ngeow, J., Skull, S. & Biggs, B-A. (2007). Health services utilisation and barriers for settlers from the Horn of Africa. *Australian and New Zealand Journal of Public Health*, 31(4). <http://dx.doi.org/10.1111/j.1753-6405.2007.00081.x>

North West mental wellbeing survey. Employment and resilience. (2009). NHS North West.

Retrieved from

<http://www.champspublichealth.com/writedir/3cb2Employment%20and%20resilience.pdf>

Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D. & Southwick, S. (2007). Social support and resilience to stress: from neurobiology to clinical practice. *Psychiatry*, 4(5), 35–40.

Padula, M. A. (1995). Assessment issues in families of individuals with disabilities. *Family Assessment*, ed. Jane Close Conoley & Elaine Buterick Werth (Lincoln, NE: Buros Institute of Mental Measurements, University of Nebraska-Lincoln).

Panhwar, A. H., Ansari, S., Shah, A. A. (2017). Post-positivism: An effective paradigm for social and educational research. *International Research Journal of Arts and Humanities*, 45(45), 256–259

- Pargament, K. I. (1987). *'God help me': Towards a theoretical framework of coping for the psychology of religion*. Paper presented at the American Psychological Association, New York City.
- Patton MQ. Qualitative research and evaluation methods. 3rd Sage Publications; Thousand Oaks, CA: 2002.
- Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I. & Nardocci, F. (2018). Parental burden and its correlates in families of children with autism spectrum disorder: A multicentre study with two comparison Groups. *Clinical Practice and Epidemiology in Mental Health*, 14, 143–176. <https://doi.org/10.2174/1745017901814010143>
- Polit, D. F. & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Productivity Commission. (2017). *National Disability Insurance Scheme (NDIS) costs: Study report*. Canberra, ACT: Author. Retrieved from <https://www.pc.gov.au/inquiries/completed/ndis-costs#report>
- Ravindran, N., & Myers, B. J. (2013). Beliefs and practices regarding autism in Indian families now settled abroad: An internet survey. *Focus on Autism & Other Developmental Disabilities*, 28(1), 44-53. <http://dx.doi.org/10.1177/1088357612458970>
- Reavley, N., Bassilios, B., Ryan, S., Schlichthorst, M. & Nicholas, A. (2015). *Interventions to build resilience among young people: A literature review*. Victorian Health Promotion Foundation. Retrieved from <https://www.vichealth.vic.gov.au/-/media/ResourceCentre/PublicationsandResources/Mental-health/Interventions-to->

build-resilience-among-young-

people.pdf?la=en&hash=52060B1A4407D7FDCB24945F32DF675B012385A4

Refugee Council of Australia. (2019). *The National Disability Insurance Scheme*. Retrieved from <https://www.refugeecouncil.org.au/disability-report/10/>

Reis, HT.; Clark, MS.; Holmes, JG. 2004. Perceived partner responsiveness as an organizing construct in the study of intimacy and closeness. In: Mashek, DJ.; Aron, A., editors. *Hand book of closeness and intimacy*. Mahwah, NJ: Lawrence Erlbaum Associates Publishers; 201-225.

Riggio, N. R., & Avalos, B. I. (2017). Parenting challenges and resilience of Latino Immigrant Parents. *Electronic Theses, Projects, and Dissertations*, 469. Retrieved from <http://scholarworks.lib.csusb.edu/etd/469>

Rosa, F., Bagnasco, A., Aleo, G., Kendall, S., & Sasso, L. (2017). Resilience as a concept for understanding family caregiving of adults with Chronic Obstructive Pulmonary Disease (COPD): An integrative review. *Nursing Open*, 4(2).

Ross, T. (2012). *A survival guide for health research methods*. Berkshire, England: Open University Press, McGraw-Hill.

Rowbotham, M., Carroll, A. & Cuskelly, M. (2011). Mothers' and fathers' roles in caring for an adult with an intellectual disability. *International Journal of Disability, Development, and Education*, 58(3), 223–240.

Ryan, Sara. (2010). 'Meltdowns', surveillance and managing emotions; going out with children with autism. *Health & Place Journal*, 16(5), 868–875.

<https://doi.org/10.1016/j.healthplace.2010.04.012>

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340.

- Sandhu, P., Ibrahim, J. & Chinn, D. (2017). 'I wanted to come here because of my child': Stories of migration told by Turkish-speaking families who have a son or daughter with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(2): 371–382.
- Schapiro, N. A., Kools, S. M., Weiss, S. J. & Brindis, C. D. (2013). Separation and reunification: The experiences of adolescents living in transnational families. *Current Problems in Pediatric & Adolescent Health Care*, 43(3), 48–68.
<https://doi.org/10.1016/j.cppeds.2012.12.001>
- Scott, C. B. (2013). Alzheimer's disease caregiver burden: Does resilience matter? *Journal of Human Behavior in the Social Environment*, 23(8), 879-892.
<http://dx.doi.org/10.1080/10911359.2013.803451>
- Senturk, S. G., Akyol, M. A. & Kucukguclu, O. (2018). The relationship between caregiver burden and psychological resilience in caregivers of individuals with dementia. *International Journal of Caring Sciences*, 11(2), 1223–1230.
- Shah, R. J., Collard, H. R. & Morisset, J. (2018). Burden, resilience and coping in caregivers of patients with interstitial lung disease. *Heart & Lung: The Journal of Acute & Critical Care*, 47, 264–268.
- Sharma, G. (2017). Pros and cons of different sampling techniques. *International Journal of Applied Research*, 3(7), 749-752
- Shenfield, T. (2017). Understanding The Challenges Faced by Immigrant Children. Retrieved from <http://www.psy-ed.com/wpblog/challenges-faced-by-immigrant-children/>
- Shtutman, T. (2015). Immigration and disability: The Russian Jewish experience. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 77(4-B(E)).

- Skotarczak, L. & Lee, G. K. (2015). Effects of parent management training programs on disruptive behavior for children with a developmental disability: A meta-analysis. *Research in Developmental Disabilities, 38*, 272–287.
<https://doi.org/10.1016/j.ridd.2014.12.004>
- Spilka, B., Shaver, P. & Kirkpatrick, L. (1985). A general attribution theory for the psychology of religion. *Journal for the Scientific Study of Religion, 24*: 1–20.
- Sritharan, B., Koola, M. (2019). Barriers Faced By Immigrant Families of Children with Autism: A Program To Address The Challenges. *Asian Journal of Psychiatry, Volume 39*, 53-57. <https://doi.org/10.1016/j.ajp.2018.11.017>.
- Steiner, I. & Landös, A. (2019). Surveying migrants in Europe. Experiences of the Swiss Migration-Mobility Survey. In I. Steiner & P. Wanner (Eds.), *Migrants and expats: The Swiss migration and mobility nexus* (pp. 21–54). Cham, Switzerland: Springer International Publishing.
- Stevens, C. S. (2010). Disability, caregiving and interpellation: migrant and non-migrant families of children with disabilities in urban Australia. *Disability & Society, 25*(7), 783-796.
- Straiton, M. L., Aambø, A. K. & Johansen, R. (2019). Perceived discrimination, health and mental health among immigrants in Norway: The role of moderating factors. *BMC Public Health, 19*(1). doi:10.1186/s12889-019-6649-9
- Strohm, K. (2017). *General issues around the implementation and performance of the NDIS Submission 15*. Siblings Australia. Retrieved from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS/Submissions

- Su, Y-R. (2008). Parenting in a foreign land: The lived experience of Taiwanese immigrants with disabled children in the United States. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 68(10-B), 66271.
- Sue, D. W., & Sue, D. (2012). Counseling the culturally diverse: Theory and practice. John Wiley & Sons.
- Szaflarski, M., & Bauldry, S. (2019). The Effects of Perceived Discrimination on Immigrant and Refugee Physical and Mental Health. *Advances in medical sociology*, 19, 173–204. <https://doi.org/10.1108/S1057-629020190000019009>
- Tariq, S. & Woodman, J. (2013). Using mixed methods in health research. *Journal of the Royal Society of Medicine*, 4(6). <https://doi.org/10.1177/2042533313479197>
- Tay, K. C. P., Seow, C. C. D., Xiao, C., Lee, H. M. J., Chiu, H. F., & Chan, S. W.-C. (2016). Structured interviews examining the burden, coping, self-efficacy, and quality of life among family caregivers of persons with dementia in Singapore. *Dementia*, 15(2), 204–220. <https://doi.org/10.1177/1471301214522047>
- Thagard, P. (2016). *Spiritual but not religious. Does it make sense to reject religion while maintaining spirituality?* Retrieved from <https://www.psychologytoday.com/us/blog/hot-thought/201610/spiritual-not-religious>
- Thomas, F. & Sumathi, G. N. (2018). Length of stay and acculturative stress of international students: Empirical study. *International Journal of Pure and Applied Mathematics*, 120(6), 10253–10264.
- Tiong, A., Patel, M., Gardiner, J., Ryan, R., Linton, K., Walker, K., ... Biggs, B-A. (2006). Health issues in newly arrived African refugees attending general practice clinics in Melbourne. *The Medical Journal of Australia*, 185(11): 602–606. <https://doi.org/10.5694/j.1326-5377.2006.tb00724.x>.

Toki, M., Washio, M., Furukawa, A., Narita, H., Yokogushi, K. & Ishiai, S. (2010).

Investigating parental caregiver burden for children with disabilities using a Japanese version of the Zarit Caregiver Burden Interview (J-ZBI). *The Japanese Journal of Rehabilitation Medicine*, 47, 396–404.

<http://doi.org/10.2490/jjrmc.47.396>

Triandis, Harry C. (2015). Collectivism and individualism: Cultural and psychological concerns. In *International encyclopedia of the social & behavioral sciences* (2nd ed.) (pp. 206–210). <https://doi.org/10.1016/B978-0-08-097086-8.24008-7>

Twoy, R., Connolly, P. M. & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *J Am Acad Nurse Pract*, 19(5), 251–260.

<http://doi.org/10.1111/j.1745-7599.2007.00222.x>

Uchino, B. N. (2004). *Current perspectives in psychology. Social support and physical health: Understanding the health consequences of relationships*. Yale University Press. <https://doi.org/10.12987/yale/9780300102185.001.0001>

United Nations Department of Economic and Social Affairs. (2019). *International migrant stock 2019*. Retrieved from

https://www.un.org/en/development/desa/population/migration/publications/migrationreport/docs/MigrationStock2019_TenKeyFindings.pdf

United Nations High Commissioner for Refugees. (2019). *Global Report 2018*. UNHCR:

The UN Refugee Agency. Retrieved from

http://reporting.unhcr.org/sites/default/files/gr2018/pdf/GR2018_English_Full_lowres.pdf

Wagnild, G. (2009). A review of the Resilience Scale. *Journal of Nursing Measurement*,

17(2), 105–113. <http://dx.doi.org/10.1891/1061-3749.17.2.105>

- Walsh, H. A. (2017). Cultural considerations in the delivery of homecare services: Beyond 2 kitchens and a disability/piu di due cucine e disabilita. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 77(7-A(E)), No Pagination Specified.
- Wang, H.-T. & Casillas, N. (2012). Asian American parents' experiences of raising children with autism: Multicultural family perspective. *Journal of Asian and African Studies*, 48(5), 594–606.
- Wathum-Ocama, J. C., & Rose, S. (2002). Hmong immigrants' views on the education of their deaf and hard of hearing children. *American Annals of the Deaf*, 147(3), 44-53.
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553. <http://dx.doi.org/10.1111/j.1365-2648.2005.03621.x>
- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, 21(2), 152–169. <https://doi.org/10.1017/S0959259810000420>
- Woodgate, R., Busolo, D., Crockett, M., Dean, R., Amaladas, M., & Plourde, P. (2017). A qualitative study on African immigrant and refugee families' experiences of accessing primary health care services in Manitoba, Canada: it's not easy!. *International Journal for Equity in Health*, 16(5), <https://doi.org/10.1186/s12939-016-0510-x>
- World Health Organisation. (2001). International Classification of Functioning, Disability and Health ICF. Geneva, Switzerland: WHO.
- World Health Organisation. (2012). *Early childhood development and disability: A discussion paper*. Malta: World Health Organization and UNICEF. Retrieved from [https://www.unicef.org/disabilities/files/ECD-and-Disability-WHO-2012\(1\).pdf](https://www.unicef.org/disabilities/files/ECD-and-Disability-WHO-2012(1).pdf)

- World Health Organisation. (2018). Health promotion for improved refugee and migrant health. Copenhagen, Denmark: WHO.
- Ye, ZJ., Qiu ,HZ., Li, PF., Liang, MZ., Wang, SN. & Quan, XM. (2017). Resilience model for parents of children with cancer in mainland China-An exploratory study. *European Journal of Oncology Nursing*, 27, 9-16
- Yu, B. (2013). Issues in bilingualism and heritage language maintenance: Perspectives of minority-language mothers of children with autism spectrum disorders. *American Journal of Speech-Language Pathology*, 22(1), 10–24.
[https://doi.org/10.1044/1058-0360\(2012/10-0078\)](https://doi.org/10.1044/1058-0360(2012/10-0078))
- Zarit, S., Reever, K. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, 649–655.
- Zechella, A. N. & Raval, V. V. (2016). Parenting children with intellectual and developmental disabilities in Asian Indian families in the United States. *Journal of Child and Family Studies*, 25(4), 1295–1309. <http://dx.doi.org/10.1007/s10826-015-0285-5>
- Zeidner, M. & Saklofske, D. (1996). Adaptive and maladaptive coping. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research, applications* (pp. 505–531). John Wiley & Sons.
- Zhou, Q. (2015). Accessing disability services by people from culturally and linguistically diverse backgrounds in Australia. *Disability and Rehabilitation*, 38(9), 844–859.
<https://doi.org/10.3109/09638288.2015.1062925>
- Zhu, N. & Chang, L. (2019). Evolved but not fixed: A life history account of gender roles and gender inequality. *Frontiers in Psychology*, 10(1709).
[doi:10.3389/fpsyg.2019.01709](https://doi.org/10.3389/fpsyg.2019.01709)

Zimmermann, K. (2017). *What is culture?* Retrieved from

<https://www.livescience.com/21478-what-is-culture-definition-of-culture.html> in

13/10/2019

Zong, J., Batalova, J. & Burrows, M. (2019). *Frequently requested statistics on immigrants*

and immigration in the United States. MPI: Migration Policy Institute. Retrieved

from [https://www.migrationpolicy.org/article/frequently-requested-statistics-](https://www.migrationpolicy.org/article/frequently-requested-statistics-immigrants-and-immigration-united-states?gclid=EAIaIQobChMI7NSfoZG75gIViBaPCh2iqQ6EEAAYASAAEgJxNv)

[immigrants-and-immigration-united-](https://www.migrationpolicy.org/article/frequently-requested-statistics-immigrants-and-immigration-united-states?gclid=EAIaIQobChMI7NSfoZG75gIViBaPCh2iqQ6EEAAYASAAEgJxNv)


[states?gclid=EAIaIQobChMI7NSfoZG75gIViBaPCh2iqQ6EEAAYASAAEgJxNv](https://www.migrationpolicy.org/article/frequently-requested-statistics-immigrants-and-immigration-united-states?gclid=EAIaIQobChMI7NSfoZG75gIViBaPCh2iqQ6EEAAYASAAEgJxNv)

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Appendices

Appendix A: Published Literature Review

Challenges, Coping, and Resilience Among Immigrant Parents Caring for a Child With a Disability: An Integrative Review

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Key words

Challenges, child, coping, disability, immigrant, parent, resilience

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Abstract

Purpose: The aim of this integrative review is to synthesize quantitative and qualitative research evidence on challenges in caring for a child with a disability among immigrant parents and to understand their coping strategies and resiliency factors associated with their coping.

Methods: A comprehensive literature search was conducted to identify relevant studies from the following databases: MEDLINE, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, PsycINFO, Social work abstract, Cochrane library, and EMBASE.

Findings: This review included 25 studies: 1 quantitative, 23 qualitative, and 1 narrative review. The main challenges that parents faced were language barriers, financial hardships, service utilization challenges, poor adaptation to new culture, stigma related to mental illness, discrimination, and social isolation. This review found poor communication and lack of cultural awareness among some healthcare professionals. Immigrant parents used problem-focused coping, avoidance coping, spiritual coping, and social support to manage their challenges. Parents who received social, emotional, and instrumental support were more resilient. Personality traits and faith were protective factors that enhanced resilience.

Conclusions: When immigration and disability are considered concurrently, the burden of care multiplies. Immigrant parents with children who have disabilities faced extra challenges related to adaptation, finance, service utilization, and stigma. Healthcare providers can play an important role in aiding these parents in service utilization and adaptation.

Significance: This review adds new knowledge on immigrant parents' challenges in caring for their children with disabilities. Such knowledge could help health professionals to develop supportive interventions to enhance parental coping and resilience.

Clinical Relevance: Culturally appropriate and sensitive communication and care provided by healthcare providers can facilitate service utilization and reduce perceived stigma. Special training provided to healthcare providers regarding the challenges of these families may enhance awareness. Information support and parental support groups may help to enhance parental coping and reduce isolation. An interpreting service should be provided in all aspects of care.

[Correction added on November 30, 2019 after first online publication: The author Regina Lai Tong Lee's job title was changed to "Professor".]

Parenting a child with a disability is demanding and poses many challenges to parents and the family. These challenges, which are not necessarily specific to immigrant parents, may include caring for the child with a disability, managing the child's behavioral problems, financial hardship, poor social adjustment, social isolation, and frustration with the healthcare system (Keenan, Runyan, & Nocera, 2006; Murray, Maslany, & Jeffery, 2006).

Being new immigrants in a host country can further complicate parenting experiences (Riggio & Avalos, 2017). Immigrant parents attempt to rebuild their lives in a new home in a new country. They face challenges such as adapting to changes in family relationships, learning a new language and new social rules, applying for new citizenship, finding a new job, and adjusting to a new environment and culture (Riggio & Avalos, 2017). On top of language barriers, immigrant children face extra challenges, such as experiencing bullying in schools and adapting to different types of food, clothes, and customs (Shenfield, 2017).

When immigration and disability are considered concurrently, restrictions multiply and result in a challenging experience for the parents and the whole immigrant family (Khanlou, Mustafa, Vazquez, Haque, & Yoshida, 2015). With increasing global immigration, children with disabilities have immigrated with their parents. An Australian study found that people from different cultural backgrounds have a similar level of disability as Australia-born people (18.5%), but have a greater rate of profound and severe disability and a higher level of need for assistance in undertaking core activities (Zhou, 2016). We do not have an adequate understanding of the perceived challenges of immigrant parents on taking care of their children with disabilities, or of their resilience and coping strategies. An integration of both quantitative and qualitative empirical evidence would contribute to a deeper understanding of the relationship between immigration and taking care of children with disabilities, parents' perceived challenges, and their resilience and coping strategies. Therefore, the aims of this integrative literature review were to synthesize evidence on challenges in caring for children with disabilities among immigrant families, coping strategies used by immigrant parents to manage their children's disabilities, and resiliency factors associated with their coping.

Methods

This integrative literature review was conducted using a five-stage approach: problem identification, literature search, data evaluation, data analysis, and presentation (Whittemore & Knafl, 2005). This approach has been

used extensively to enhance the rigor of the review process in many published integrative reviews (Hopia, Latvala, & Liimatainen, 2016).

Literature Search

An extensive search of the literature was conducted that included both qualitative and quantitative primary and secondary studies. The databases searched included MEDLINE, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, PsycINFO, Social work abstract, Cochrane library, and EMBASE using the identified key words "immigrant", "developmental disability*", "coping", "resilience", "stigma*" and "need*". The search included articles published in English between the years 2000 and 2017. Table S1 lists the critical search terms and expanded terms. The search used all the key words and index terms across all databases. During the search process, consideration was given to the diverse terminology used, synonyms, and spelling of key words. We also conducted a manual search. In the key word search, the terms "challenges," "burdens," "needs," and "concerns" were used. Because all these words are used interchangeably in the literature, we used the term "challenges" to report the findings in this integrative review.

Inclusion and Exclusion Criteria

This review included studies that focused on immigrant parents (mothers or fathers) who had one or more children (<18 years old) with disabilities and had migrated to their host country regardless of their immigration period. Studies that explored service providers' perspectives on immigrant parents' experiences in caring for children with disabilities were included. This review excluded studies focusing on experiences of immigrant parents of adult children with a disability. Literature that only focused on immigrant parents' challenges during the child's diagnosis were excluded. We also excluded literature published in languages other than English.

The initial search identified 1,206 titles. Another seven articles from references and citations that were seemingly relevant were retrieved and assessed. We excluded duplicated entries, leaving 742 titles. The title, abstract, and whole text were assessed based on the inclusion and exclusion criteria. A total of 715 articles were removed, with 27 articles remained.

Data Evaluation

The 27 articles were appraised for quality using the Joanna Briggs Institute (JBI) Assessment and Review

Instruments (JBI, 2014). After the appraisal, two qualitative studies were excluded because of incongruity between the research methodology data collection method, data analysis, and interpretation of results (Decoteau, 2017; Ravindran & Myers, 2013). Ultimately, 25 studies were included in this review: 23 qualitative studies, 1 quantitative study, and 1 narrative review. Figure S1 depicts the search procedure and outcome.

Data Analysis

Once each study had been fully assessed for inclusion, another independent reviewer confirmed the included studies. Data were extracted from each study. The reviewers identified themes related to parental challenges, parental coping, and resiliency factors. Data were extracted independently by two reviewers into a summary table to capture the following information: author, year published, country of origin, study design, method, sampling approach, and key findings for each study. Next, all reviewers met to corroborate findings and agree on the final list of extracted data. As in prior steps, if a discrepancy was noted, it was discussed among all the reviewers to obtain consensus. Once complete, a summary table of the findings was generated (Table S2).

The subthemes identified during the data reduction phase were then independently placed by all reviewers into matrices around the themes parental challenges, parental coping, or resiliency factors associated with parental coping. The reviewers referred back to the primary source as needed to verify context and help clarify the subthemes. A master list was generated, and the final placement of each subtheme into a theme was determined through reviewers' consensus. The reviewers then synthesized the important elements and conclusions for each theme into an integrated summation. Themes and subthemes were generated from the findings, which reflected the aims of the review (Table S3).

Findings

Data Presentation

Seventeen reviewed studies were conducted in the United States, four in the United Kingdom, three in Canada, and one in Australia. There were 287 participants, with 190 mothers, 53 fathers, and 27 service providers in the 25 reviewed studies. All immigrant parents included in this review spoke English as a second language. Immigrant parents included in this review were Russian, Indian, Mexican, Somali Bantu,

South Asian, Taiwanese, South Korean, Haitian, Pakistani, and Asian populations that were not specified.

Challenges of Raising Children With Disabilities

Language barriers. Two qualitative studies (one from the United States, one from Canada) using semistructured interviews revealed that language barriers are a challenge for immigrant parents in schools (Lai & Ishiyama, 2004; Wathum-Ocama & Rose, 2002). Parents perceived that English speaking teachers of special needs' schools had limited understanding of their needs. Interpreting services were only provided in occasional formal meetings with school staff, not in day-to-day interactions (Lai & Ishiyama, 2004; Wathum-Ocama & Rose, 2002).

In the healthcare context, immigrant mothers in the United States perceived limited English proficiency as the greatest barrier in forming meaningful partnerships with healthcare professionals (Lee & Park, 2016). Parents were perceived by healthcare professionals as passive in accessing health services. Parents were perceived as unable to attend to the child's needs or provide appropriate care (Lee & Park, 2016). A phenomenological study conducted in the United States on Russian Jewish immigrant mothers found that the mothers struggled in navigating health and school systems due to limited English proficiency. Even for immigrant parents who were proficient in speaking English, they considered many jargons used by healthcare professionals to be incomprehensible (Shtutman, 2016). Another qualitative study found that parents perceived a lack of written communication in their native language as a challenge in navigating the healthcare system (Blanche, Diaz, Barretto, & Cermak, 2015).

Financial hardship. Khanlou and colleagues (2015) found that financial hardship was a crucial challenge among fathers. They had inadequate employment opportunities, which reduced family income and sometimes resulted in poverty. Asian Indian immigrant mothers living in the United States reported high costs of raising a child with a disability, such as assessment and specialist fees. They quit their jobs and lost their income because they needed to devote more time to their children with disabilities (Narayan, 2015).

Mexican immigrant mothers raising children with disabilities in the United States reported that they faced financial crises because of medical care expenses for their children. This difficulty was intensified by their undocumented status because they were not eligible for assistance such as health insurance (Alvarado, 2004).

Services utilization challenges. In the United States, Somali Bantu immigrant parents shared challenging experiences in accessing services for their children with disabilities, particularly in the school and healthcare systems. The immigrant parents reported that they did not receive the level of care and sensitivity that would have been expected within their culture (Beatson, 2013). Lack of cultural awareness among health professionals was also voiced by Asian Muslim immigrant parents raising children with autism in the United States. The parents avoided utilizing healthcare services because they perceived European-American professionals as being cold and abrupt, spending less time interacting with them, and showing little or no interest in their cultural background (Jegatheesan, Fowler, & Miller, 2010). Other immigrant parents reported that they tried to disengage from the health and social services because they felt that the services were culturally inappropriate (Bradby et al., 2007; Narayan, 2015).

Khanlou, Haque, Sheehan, and Jones (2015) explored the perspective of Canadian service providers (social work, health services, legal services, and community services) on the challenges encountered by immigrant mothers with children who had disabilities in accessing social support and services. Service providers stated that immigrant mothers did not use the available services because they were not able to fill out the comprehensive assessment forms that were required from the service organizations, although the majority of mothers appreciated the services once they used them. Some immigrant parents were not aware of their right to access those free available services (Khanlou, Haque, et al., 2015).

Transportation was found to be a challenge. Attending medical appointments for a child with a disability was a challenge due to inconvenient public transportation. This is of special relevance because new immigrant families often settled in peripheral suburbs where the rent was cheaper, but health and social services were mainly located in the city center (Khanlou, Haque, et al., 2015; Khanlou, Mustafa, et al., 2015).

Poor adaptation to a new culture. Shtutman's (2016) study found that cultural differences were confusing to immigrant parents. For instance, to smile and talk to a stranger is considered normal behavior in the United States, but not for Russian Jews. Immigrant families found it difficult to adapt to their host country's norms and customs. As a result, they reported dissimilation to the dominant culture (Shtutman, 2016). South Asian parents living in the United Kingdom viewed adapting to a new culture as an additional burden that

compounded the existing burdens of raising a child with a disability (Heer, Larkin, & Rose, 2015).

Stigma related to mental illness. Bradby and colleagues (2007) explored the experience of immigrant parents in the United Kingdom using the Child and Adolescent Mental Health Services. Parents reported feeling ashamed of their children's mental health problems. They were concerned about gossip among their own community. Mothers of children with attention deficit hyperactivity disorder (ADHD) living in the United States similarly stated that they felt stigmatized. They worried that they would bring shame to their family if they sought help from psychiatrists or psychologists (Al-Azzam, 2011).

Two studies found immigrant parents reported feeling stigmatized due to the challenging behaviors of their children with disabilities, such as violent outbursts. These behaviors were considered culturally inappropriate and were not tolerated by their local community. This stigma resulted in families' tendency to hide their children at home and to delay help seeking (Fox, Aabe, Turner, Redwood, & Rai, 2017; Ijalba, 2016). Parents were isolated from their extended family and community (Blanche et al., 2015). Khanlou, Mustafa, and colleagues (2015) found that immigrant parents felt strongly that they were social outcasts not only by the community, but by their families, who tended to blame them for their child's condition.

Discrimination. Immigrant parents reported experiencing discrimination in both their home and host countries (Su, 2008). A study of Taiwanese families living in the United States found that one of the main reasons for their immigration was to find a place that would be more accepting of their children with disabilities. However, they were shocked to find that their children were also not being accepted and being rejected in multiple situations by their new host country (Su, 2008). Similarly, South Korean immigrant parents living in the United States reported feeling discriminated by their own community in the host country due to their child's disability (Kwon, 2016). South Asian parents in the United Kingdom raising children with mental illnesses such as ADHD, autism, and disruptive antisocial behavior reported discriminatory treatment in education, health, and social care. They attributed this discrimination as being based on ethnicity, due to their status as a minority group (Bradby et al., 2007).

Social isolation. Stevens (2010) explored the experience of immigrant parents from different countries such as Lebanon, Vietnam, Croatia, East Timor, Turkey,

the Philippines, and China who migrated to Australia and were caring for children with disabilities. Immigrant parents expressed that there was no one they could rely on for help and emotional support. They experienced a sense of isolation due to their migrant status and carer responsibilities (Stevens, 2010).

Other researchers also found that immigrant parents experienced loneliness and struggled without a support system (Shtutman, 2016), even though they lived with their extended families in the host country. They reported social isolation because of not being accepted by their extended family due to raising children with disabilities (Narayan, 2015). Southeast Asian parents reported that caring for their children with disabilities could be physically and psychologically demanding, as well as time consuming, all of which restricted their social activities (Luong, Yoder, & Canham, 2009).

Coping Strategies Used by Immigrant Parents of Children With Disabilities

Problem-focused coping. Haitian immigrant parents raising children with disabilities in the United States tended to use problem-solving coping strategies. They identified the challenges and then attempted to minimize the negative outcome. The more educated parents tended to find direct solutions to problems, while those who were less educated developed ways to avoid factors that might trigger their child's challenging behaviors, particularly in social gatherings (Gregoire, 2011). Wang and Casillas (2012) reported the experiences and coping mechanisms of Mandarin-speaking parents raising children with disability in the US. Parents confronted their challenges by searching for knowledge related to their child's disability and looking for appropriate community resources (Wang & Casillas, 2012).

Avoidance coping. Some parents reported that they avoided expressing their concerns regarding their child's difficulties because they worried that stories about their problems would leak back to their village of origin (Blanche et al., 2015). South Asian immigrant parents claimed that they avoided social gatherings because they felt their own community did not understand their child's condition. Parents avoided social events because of the discomfort with having their child's challenging behaviors judged by others (Luong et al., 2009).

Spiritual coping. Southeast Asian immigrant parents in Luong and colleagues' (2009) study sought religious support, such as praying at home, to maintain a sense of hope. Somali immigrant parents raising children

with autism expressed that their faith was a source of comfort that helped them to cope. They described Allah-God as being in control of their lives, and they voiced gratitude and trust in Allah's plan for the future (Fox et al., 2017). Similarly, South Korean immigrant parents explained that religion and spirituality were powerful coping mechanisms or a source of comfort, peace, and hope (Kwon, 2016). Pakistani parents who lived in the United Kingdom believed that their child's disability was from God. They sought help from religious sources, such as visiting temples, which was considered an acceptable and helpful aid to manage their child's disability (Croot, Grant, Mathers, & Cooper, 2012).

Social support. Mothers who primarily shouldered the care burden for their child with a disability concurred that support from other family members, especially from spouses, played a critical role in their coping. When fathers accepted their child's disability and supported their partners, the mothers were more able to comfortably reach out to other informal social support groups and developed relationships with other parents with a similar situation (Lee & Park, 2016).

Support groups that bring together families facing the same situation were found to be effective. Parents appreciated the opportunity to develop supportive relationships with other immigrant families raising children with disabilities. Support groups provided parents not only with information but also with encouragement, support, reassurance, optimism, and hope (Khanlou, Haque, et al., 2015; Lee & Park, 2016). A quantitative study in the United States among Indian immigrant parents of children and adolescents with developmental disabilities found a negative correlation between parents' perceived quality of social support and their overall stress levels. Perceived quality of social support facilitated their coping and thus reduced their stress levels. The participants ranked their spouse as their most significant source of support, followed by support groups and friends. Only 18.2% of these parents perceived support provided by doctors as excellent, and 3% of parents perceived healthcare providers and nurses as an excellent source of support (John, Bower, & McCullough, 2016).

Immigrant families also used social support services such as schools, social workers, and interpreting services to target their specific problems (Croot et al., 2012). Asian Indian immigrant parents in the United States stated that when they were able to access resources in the school or in the community, they felt less lonely and their needs were being met (Zechella & Raval, 2016).

Resiliency Factors Associated With Parental Coping

Resiliency Protective Factors. Four studies explored resiliency factors associated with parental coping. The findings revealed that immigrant parents who received social and emotional support from their family seemed to be resilient. Other parents who received instrumental support, such as being employed in a professional job, speaking English fluently, earning a high income, having a driver's license, or being more educated, appeared more resilient (Heer et al., 2015; Su, 2008; Zechella & Raval, 2016). A combination of two or more of these resources led to more resilient parents (Su, 2008). Service providers in the report of Khanlou, Haque, et al. (2015) stated that parents who received social, instrumental, and emotional support from their families and from care providers seemed to be more resilient.

Other parents reported that their personality traits and faith were the vital factors that contributed to their resilience. Although these parents could not speak English, and had low socioeconomic status, their resilience was similar to that of other parents. This was because those parents had optimistic and flexible personalities, and they had their own religious beliefs and were often involved in their faith communities (Su, 2008; Zechella & Raval, 2016).

Discussion

This review found that immigrant parents raising children with disabilities had key challenges, including limited English proficiency and services utilization. Language barriers limited the communication and negotiation between immigrant parents and healthcare providers. This created a barrier to access services that were available for their children with disabilities in the host country.

In contrast to the beliefs that service providers should be supportive to immigrant parents, this review found that parents perceived discrimination by their service providers. Immigrant parents perceived poor interaction with healthcare professionals due to the providers' lack of cultural awareness to take care of immigrant parents. It was regarded by parents as the core challenge that hindered the utilization of services (Jegatheesan et al., 2010). However, Jegatheesan et al.'s (2010) findings were from the perspective of the immigrant parents, which could be a subjective view. Other studies conducted to measure cultural awareness of healthcare professionals who provided care to those parents revealed lack of training in providing culturally sensitive care

(Grandpierre et al., 2018; Lindsay, King, Klassen, Esses, & Stachel, 2012).

Financial hardships were reported by most of the immigrant parents who lived in the United States. That might be related to healthcare expenses in the United States (Kaiser Family Foundation, 2019). Not all immigrants who live in the United States are eligible for public health coverage such as Medicaid. Immigrant parents explained that due to the care demands for a child with disability, they needed to stay at home or worked only part time, thus losing income (Khanlou, Mustafa, et al., 2015). One of the reports on this issue was a narrative review (Khanlou, Mustafa, et al., 2015) that included 59 studies, but the origin of the included studies was not mentioned.

It is well documented in the literature that immigrant families in different countries face similar challenges, such as language challenges, financial challenges, and social isolation (Hurtado-de-Mendoza, Gonzales, Serrano, & Kaltman, 2014; Woodgate et al., 2017). However, immigrant parents raising children with disabilities face extra challenges. For example, in addition to language barriers, they reported being isolated due to embarrassment caused by their children's disruptive behavior in public. They used healthcare services more than other immigrant parents due to their children's health status. Thus, they experienced more difficulties in navigating the health system than immigrant parents who had children without disabilities. The pressures of adapting to a new culture, along with taking care of children with disabilities, increase the burden of care for these immigrant parents. Healthcare professionals need to understand and be sensitive to the needs of these parents and provide culturally appropriate support and care.

In the present review, 24 studies were related to immigrant parents' perspectives. Only one study explored the service providers' perspectives. Children with disabilities are most likely to utilize healthcare services such as hospitals and child health centers due to their ongoing complex healthcare needs (Khanlou, Haque, et al., 2015). Service providers may have unique perspectives on the care that immigrant families should receive. Future studies should address this gap.

This review found that immigrant parents used various coping strategies to manage their caregiving challenges. In addition to seeking social support, some immigrant parents identified religion, prayer, and spirituality as a coping mechanism that provided them with comfort or hope (Croot et al., 2012; Fox et al., 2017; Kwon, 2016; Luong et al., 2009). The literature suggested that religious beliefs can shape a person's

psychological perception of pain or disability as they create a mindset that enables the person to relax and allow healing on its own (Joshi, Kumari, & Jain, 2008). These behaviors include trying to find a lesson from God in the stressful event, doing what one can do and leaving the rest in God's hands, and seeking support from church members (Joshi et al., 2008). This review yielded similar findings, which highlighted the importance of spiritual support and care.

Having a support system of family and friends whom they could spend time with and rely on was a vital factor that helped immigrant families to manage their challenges (Khanlou, Haque, et al., 2015). Additional support from healthcare professionals, such as emotional support and information support for caregivers, has also been reported to enhancing caregivers' abilities in managing their challenges (Leow & Chan, 2017). Parental support groups may also help to enhance peer support.

The cultural values and beliefs of the parents' home country may affect their perceived challenges, coping process, and even access to healthcare services. Most immigrant parents do not realize that access to health and education are their basic rights, so they do not actively seek the resources they need for their children. Parents' cultural beliefs and values may also influence how they access available services, follow up with treatment, and view their child's disability. In some cultures, disability is associated with stigma and a sense of shame (Koschorke et al., 2017). If this stigma is not adequately addressed, some parents may avoid access to health care and/or social services and may face social isolation and social exclusion. Cultural values and beliefs may also affect parental coping processes such as social support, faith, and belief in God. The value of extended families for social support was often described by parents as important. Thus, it is not only the immigration status that impacts parental experience in raising children with disabilities (e.g., coping with language barriers, adapting to a new culture, or navigating new systems), but also immigrant parents' cultural values and beliefs.

This review found that traits such as having a flexible and optimistic personality and having faith are protective factors that allow immigrant parents to adapt well and be resilient. Resilience has a positive impact on decreasing caregivers' burdens in studies relating to chronic diseases. As caregivers' resilience increases, their caregiver burden decreases (Rosa, Bagnasco, Aleo, Kendall, & Sasso, 2017; Scott, 2013). These findings highlight the importance of interventions that enable healthcare professionals to foster greater resilience among immigrant parents of children with disabilities. Such interventions mitigate parents' burdens.

Limitations

This review has limitations. The small sample size of some studies limited the generalizability of the findings. For example, Alvarado (2004) explored the experience of two immigrant mothers in raising their children with disabilities. In a quantitative study, John et al. (2016) recruited 33 immigrant parents to examine their stressors and perceived quality of social support in raising their children with disabilities. In Jegatheesan et al.'s (2010) study, the presence of a researcher during the observation might have influenced the participants' behavior. In Stevens' (2010) study, the author is an immigrant mother who has a child with a disability, which might affect the objectivity of the study results. In this review, immigrants were examined as one category. Immigrants are not a homogeneous group. Further, the reviewed studies were conducted in four Western countries and all in English-speaking countries. Each country has its own culture and healthcare policies. This will affect the generalizability of the review results to other countries or healthcare settings. Further, there was no ethical issue reported in the reviewed studies for participants with a language barrier, their understanding of confidentiality, and protection of individual privacy.

Implications

Using interpreting services in all aspects of care provision may help to overcome the language challenges of immigrant parents and their children with disabilities. Re-evaluating translated materials, identifying the major language groups, and ensuring that translations appropriately describe and explain the pathway and access to services may help. Besides interpreters, there is a need for cultural brokers (Miklavcic & LeBlanc, 2014), that is, expert mediators with interpreter skills, familiarity with the administrative aspects of relevant government programs, and the ability to work across both governmental and nongovernmental organizations. The main role of these brokers is to provide culturally appropriate information and personalized guidance to parents on how to navigate the health and social welfare systems and access services.

Providing continuous training to healthcare providers regarding immigrant families' challenges in raising their children with disabilities may help to enhance the awareness of the challenges faced by culturally and linguistically diverse (CALD) groups (Kwon, 2016). Having more ethnically and linguistically diverse staff who are well trained in cultural competence and care of children with disabilities may also help (Khanlou, Haque, et al., 2015). Practice guidelines and policies for taking care of CALD

groups with children with disabilities could be developed to enhance the care quality.

Healthcare professionals need to understand how families respond to a certain situation and help them to reframe the situation in a more positive light. These strategies might help in forming a rapport with the immigrant parents, and to keep them returning for further help. It is also essential to encourage healthcare providers to implement supportive interventions such as engaging immigrant parents in support groups and learning activities to foster parental coping. Providing information about immigrants' basic rights and how they can access education and social support services in their host country could be useful.

This review found only one quantitative study and 24 qualitative studies. A mixed-methods design using quantitative and qualitative approaches with a larger sample size is recommended to address this phenomenon comprehensively. To have an in-depth understanding of immigrant parents' challenges in service utilization, future research could be conducted in more countries that have a large population of immigrants and include the perspective of service providers.

Conclusions

This integrative review synthesized the literature on challenges, coping strategies, and resilience in caring for children with disabilities among immigrant parents. Such knowledge is essential to encourage healthcare providers to implement supportive interventions that will increase parental coping and resilience. The implications of these findings include implementing interventions to support the special needs of immigrant parents with children who have disabilities, engaging in professional training to enhance cultural competence for healthcare providers, and adopting new policies or improving the existing policies for immigrant parents and their children with disabilities. Future studies could use a mixed-methods design with larger samples, including reports from both immigrant parents' and service providers' perspectives.

Clinical Resources

- Australian Human Rights Commission. <https://www.humanrights.gov.au/>
- European Union Agency for Fundamental Rights. <http://fra.europa.eu/>
- National Disability Insurance Scheme. <https://www.ndis.gov.au/>

References

- Al-Azzam, M. M. (2011). *Arab immigrant Muslim mothers' perceptions of children's attention deficit hyperactivity disorder (ADHD)* (Doctoral dissertation). University of Iowa, Iowa City, IA.
- Alvarado, M. I. (2004). Mucho camino: The experiences of two undocumented Mexican mothers participating in their child's early intervention program. *American Journal of Occupational Therapy*, 58(5), 521–530.
- Beatson, J. E. (2013). Supporting refugee Somali Bantu mothers with children with disabilities. *Pediatric Nursing*, 39(3), 142–145.
- Blanche, E. I., Diaz, J., Barretto, T., & Cermak, S. A. (2015). Caregiving experiences of Latino families with children with autism spectrum disorder. *American Journal of Occupational Therapy*, 69(5), p1–p11. <https://doi.org/10.5014/ajot.2015.017848>
- Bradby, H., Varyani, M., Oglethorpe, R., Raine, W., White, I., & Helen, M. (2007). British Asian families and the use of child and adolescent mental health services: A qualitative study of a hard to reach group. *Social Science & Medicine*, 65(12), 2413–2424.
- Croot, E., Grant, G., Mathers, N., & Cooper, C. (2012). Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability & Rehabilitation*, 34(18), 1540–1549. <https://doi.org/10.3109/09638288.2011.650310>
- Decoteau, C. L. (2017). The "Western disease": Autism and Somali parents' embodied health movements. *Social Science and Medicine*, 177, 169–176.
- Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2017). "It was like walking without knowing where I was going": A qualitative study of autism in a UK Somali migrant community. *Journal of Autism and Developmental Disorders*, 47(2), 305–315.
- Grandpierre, V., Milloy, V., Sikora, L., Fitzpatrick, E., Thomas, R., & Potter, B. (2018). Barriers and facilitators to cultural competence in rehabilitation services: A scoping review. *BMC Health Services Research*, 18, article 23. <https://doi.org/10.1186/s12913-017-2811-1>
- Gregoire, J. (2011). *An analysis of Haitian parents' perceptions of their children with disabilities*. Retrieved from Dissertation Abstracts International Section A: Humanities and Social Sciences, 71(8-A), 2845.
- Heer, K., Larkin, M., & Rose, J. (2015). The experiences of British South Asian carers caring for

- a child with developmental disabilities in the UK. *Tizard Learning Disability Review*, 20(4), 228–238. <https://doi.org/10.1108/TLDR-12-2014-0044>
- Hopia, H., Latvala, E., & Liimatainen, L. (2016). Reviewing the methodology of an integrative review. *Scandinavian Journal of Caring Sciences*, 30(4), 662–669. <https://doi.org/10.1111/scs.12327>
- Hurtado-de-Mendoza, A., Gonzales, F., Serrano, A., & Kaltman, S. (2014). Social isolation and perceived barriers to establishing social networks among Latina immigrants. *American Journal of Community Psychology*, 53(1–2), 73–82. <https://doi.org/10.1007/s10464-013-9619-x>
- Ijalba, E. (2016). Hispanic immigrant mothers of young children with autism spectrum disorders: How do they understand and cope with autism? *American Journal of Speech-Language Pathology*, 25(2), 200–213. https://doi.org/10.1044/2015_AJSLP-13-0017
- Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability & Society*, 25(7), 797–811. <https://doi.org/10.1080/09687599.2010.520894>
- Joanna Briggs Institute. (2014). *Joanna Briggs Institute reviewers' manual*. University of Adelaide/South Australia: Author.
- John, A., Bower, K., & McCullough, S. (2016). Indian immigrant parents of children with developmental disabilities: Stressors and support systems. *Early Child Development and Care*, 186(10), 1594–1603. <https://doi.org/10.1080/03004430.2015.1116297>
- Joshi, S., Kumari, S., & Jain, M. (2008). Religious belief and its relation to psychological well-being. *Journal of the Indian Academy of Applied Psychology*, 34(2), 345–354.
- Kaiser Family Foundation. (2019). *Health coverage of immigrants [Fact sheet]*. Retrieved from <https://www.kff.org/disparities-policy/fact-sheet/health-coverage-of-immigrants/>
- Keenan, H. T., Runyan, D. K., & Nocera, M. (2006). Child outcomes and family characteristics 1 year after severe inflicted or noninflicted traumatic brain injury. *Pediatrics*, 117(2), 317–324.
- Khanlou, N., Haque, N., Sheehan, S., & Jones, G. (2015). "It is an issue of not knowing where to go": Service providers' perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities. *Journal of Immigrant and Minority Health*, 17(6), 1840–1847. <https://doi.org/10.1007/s10903-014-0122-8>
- Khanlou, N., Mustafa, N., Vazquez, L. M., Haque, N., & Yoshida, K. (2015). Stressors and barriers to services for immigrant fathers raising children with developmental disabilities. *International Journal of Mental Health and Addiction*, 13(6), 659–674.
- Koschorke, M., Padmavati, R., Kumar, S., Cohen, A., Weiss, H., Chatterjee, S., ... Thornicroft, G. (2017). Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Social Science & Medicine*, 178, 66–77. <https://doi.org/10.1016/j.socscimed.2017.01.061>
- Kwon, J. H. (2016). *What are the experiences of South Korean immigrant parents who have a child with autism spectrum disorder*. Retrieved from Dissertation Abstracts International: Section B: The Sciences and Engineering, 76(11-B(E)).
- Lai, Y., & Ishiyama, F. (2004). Involvement of immigrant Chinese Canadian mothers of children with disabilities. *Exceptional Children*, 71(1), 97–108.
- Lee, Y. J., & Park, H. J. (2016). Becoming a parent of a child with special needs: Perspectives from Korean mothers living in the United States. *International Journal of Disability, Development and Education*, 63(6), 593–607.
- Leow, M. Q. H., & Chan, S. W. C. (2017). The challenges, emotions, coping, and gains of family caregivers caring for patients with advanced cancer in Singapore: A qualitative study. *Cancer Nursing*, 40(1), 22–30.
- Lindsay, S., King, G., Klassen, A., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers. *Disability & Rehabilitation Journal*, 34(23), 2007–2017.
- Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *Journal of School Nursing*, 25(3), 222–229. <https://doi.org/10.1177/1059840509334365>
- Miklavcic, A., & LeBlanc, M. N. (2014). Culture brokers, clinically applied ethnography, and cultural mediation. In L. Kirmayer, J. Guzder & C. Rousseau (Eds), *Cultural Consultation. International and Cultural Psychology*. New York, NY: Springer.
- Murray, H., Maslany, G., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury*, 20(6), 575–585.
- Narayan, N. (2015). *Interplay between cultural beliefs and attitudes in raising a child with intellectual disability—An Asian Indian study*. Retrieved from Dissertation Abstracts International Section A: Humanities and Social Sciences, 75(11-A(E)).
- Ravindran, N., & Myers, B. J. (2013). Beliefs and practices regarding autism in Indian families now

- settled abroad: An internet survey. *Focus on Autism & Other Developmental Disabilities*, 28(1), 44–53. <https://doi.org/10.1177/1088357612458970>
- Riggio, N. R., & Avalos, B. I. (2017). Parenting challenges and resilience of Latino immigrant parents. *Electronic Theses, Projects, and Dissertations*, 469. Retrieved from <http://scholarworks.lib.csusb.edu/etd/469>
- Rosa, F., Bagnasco, A., Aleo, G., Kendall, S., & Sasso, L. (2017). Resilience as a concept for understanding family caregiving of adults with chronic obstructive pulmonary disease (COPD): An integrative review. *Nursing Open*, 4(2), 61–75.
- Scott, C. B. (2013). Alzheimer's disease caregiver burden: Does resilience matter? *Journal of Human Behavior in the Social Environment*, 23(8), 879–892. <https://doi.org/10.1080/10911359.2013.803451>
- Shenfield, T. (2017). *Understanding the challenges faced by immigrant children*. Retrieved from <http://www.psy-ed.com/wpblog/challenges-faced-by-immigrant-children/>
- Shtutman, T. (2016). *Immigration and disability: The Russian Jewish experience*. Retrieved from Dissertation Abstracts International: Section B: The Sciences and Engineering, 77
- Stevens, C. S. (2010). Disability, caregiving and interpellation: Migrant and non-migrant families of children with disabilities in urban Australia. *Disability & Society*, 25(7), 783–796.
- Su, Y. R. (2008). *Parenting in a foreign land: The lived experience of Taiwanese immigrants with disabled children in the United States*. Retrieved from Dissertation Abstracts International: Section B: The Sciences and Engineering, 68(10-B), 6627.
- Wang, H., & Casillas, N. (2012). Asian American Parents' experiences of raising children with autism: Multicultural family perspective. *Journal of Asian and African Studies*, 48(5), 594–606.
- Wathum-Ocama, J. C., & Rose, S. (2002). Hmong immigrants' views on the education of their deaf and hard of hearing children. *American Annals of the Deaf*, 147(3), 44–53.
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Woodgate, R., Busolo, D., Crockett, M., Dean, R., Amaladas, M., & Plourde, P. (2017). A qualitative study on African immigrant and refugee families' experiences of accessing primary health care services in Manitoba, Canada: It's not easy! *International Journal for Equity in Health*, 16, article 5. <https://doi.org/10.1186/s12939-016-0510-x>
- Zechella, A. N., & Raval, V. V. (2016). Parenting children with intellectual and developmental disabilities in Asian Indian families in the United States. *Journal of Child and Family Studies*, 25(4), 1295–1309. <https://doi.org/10.1007/s10826-015-0285-5>
- Zhou, Q. (2016). Accessing disability services by people from culturally and linguistically. *Disability and Rehabilitation*, 38(9), 844–852. <https://doi.org/10.3109/09638288.2015.1062925>

Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web site:

Figure S1. Search procedure and outcome.

Table S1. Critical Search Terms and the Expanded Terms

Table S2. Summary of the Extracted Data From Reviewed Studies

Table S3. Generated Themes and Sub-Themes

Appendix B: Copyright Clearance

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Appendix C: Permissions

STEVEN HOWARD ZARIT <z67@psu.edu>

Fri 5/18/2018 11:23 PM

Ethar Alsharaydeh <Ethar.Alsharaydeh@uon.edu.au>

Dear Ethar,

Thank you for your inquiry about the Zarit Burden Interview (ZBI).

You can request permission to use the ZBI on line by registering with eProvide and then searching for the Zarit Burden Interview on their website.

<https://eprovide.mapi-trust.org/instruments/zarit-burden-interview>

Information is also provided about available translations.

There is no fee for use of the ZBI in student or unfunded academic research, but you must register and request permission on the eProvide website.

The ZBI has been used fairly often in studies of parents of children with disabilities. You want to review those studies and also the specific items in the scale. Some items are not appropriate for parents, and so you can delete them. Also, note that the word "relative" in the questions is a placeholder for the care recipient. You can change "relative" to "your child" or if you are administering the questions, use the child's name instead of "relative."

Best wishes for a successful project.

Steve Zarit

Jonathan Davidson, M.D. <jonathan.davidson@duke.edu>

Fri 5/18/2018 12:30 PM

Ethar Alsharaydeh <Ethar.Alsharaydeh@uon.edu.au>

Ethar Alsharaydeh 051718a.doc

36 KB

Dear Ethar:

Thank you for interest in the CD-RISC-10, which I would be happy to provide. Can you kindly sign and return the enclosed agreement, and remit payment of the \$30 user fee? The scale and manual will then be sent.

Kind regards,

Jonathan Davidson

Jonathan Davidson, M.D. <jonathan.davidson@duke.edu>

Fri 6/29/2018 11:54 AM

aRISC Manual 06-01-18 F.pdf

2 MB

aCD-RISC-10 01-01-18.pdf

101 KB

Dear Lindy and Ethar:

Thank you for sending payment. At your convenience, can you also kindly return the signed agreement? I have pleasure to enclose the CD-RISC-10 and user's manual.

With kind regards,

Jonathan Davidson

Appendix D: Zarit Burden Interview

0: Never, 1: Rarely, 2: Sometimes, 3: Quite Frequently, 4: Nearly Always

	Question	Score
1	Do you feel that your child asks for more help than he/she needs?	0 1 2 3 4
2	Do you feel that because of the time you spend with your child that you don't have enough time for yourself?	0 1 2 3 4
3	Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4	Do you feel embarrassed over your child's behaviour?	0 1 2 3 4
5	Do you feel angry when you are around your child?	0 1 2 3 4
6	Do you feel that your child currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7	Are you afraid what the future holds for your child?	0 1 2 3 4
8	Do you feel your child is dependent on you?	0 1 2 3 4
9	Do you feel strained when you are around your child?	0 1 2 3 4
10	Do you feel your health has suffered because of your involvement with your child?	0 1 2 3 4
11	Do you feel that you don't have as much privacy as you would like because of your child?	0 1 2 3 4
12	Do you feel that your social life has suffered because you are caring for your child?	0 1 2 3 4
13	Do you feel uncomfortable about having friends over because of your child?	0 1 2 3 4
14	Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15	Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?	0 1 2 3 4
16	Do you feel that you will be unable to take care of your child much longer?	0 1 2 3 4
17	Do you feel you have lost control of your life since your child's illness?	0 1 2 3 4
18	Do you wish you could leave the care of your child to someone else?	0 1 2 3 4
19	Do you feel uncertain about what to do about your child?	0 1 2 3 4
20	Do you feel you should be doing more for your child?	0 1 2 3 4
21	Do you feel you could do a better job in caring for your child?	0 1 2 3 4
22	Overall, how burdened do you feel in caring for your child?	0 1 2 3 4

Interpretation of Score:

- 0 - 21 little or no burden
- 21 - 40 mild to moderate burden
- 41 - 60 moderate to severe burden
- 61 - 88 severe burden

Appendix E: The Family Crisis Oriented Personal Evaluation Scales (F-COPES)

1) Strongly disagree, 2) Moderately disagree, 3) Neither agree or nor disagree,
4) Moderately agree, 5) Strongly agree

When we face problems or crises in our family, we respond by:					
1	Sharing our difficulties with relatives	1	2	3	4 5
2	Seeking encouragement and support from friends.	1	2	3	4 5
3	Knowing we have the power to solve major problems.	1	2	3	4 5
4	Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4 5
5	Seeking advice from relatives (grandparents, etc.).	1	2	3	4 5
6	Seeking assistance from community agencies and programs designed to help families in our situation.	1	2	3	4 5
7	Knowing that we have the strength within our own family to solve our problems.	1	2	3	4 5
8	Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.).	1	2	3	4 5
9	Seeking information and advice from the family doctor	1	2	3	4 5
10	Asking neighbors for favors and assistance.	1	2	3	4 5
11	Facing the problems “head-on” and trying to get solutions right away.	1	2	3	4 5
12	Watching television.	1	2	3	4 5
13	Showing that we are strong	1	2	3	4 5
14	Attending church services.	1	2	3	4 5
15	Accepting stressful events as a fact of life.	1	2	3	4 5
16	Sharing concerns with close friends.	1	2	3	4 5
17	Knowing luck plays a big part in how well we are able to solve family problems.	1	2	3	4 5
18	Exercising with friends to stay fit and reduce tension.	1	2	3	4 5
19	Accepting that difficulties occur unexpectedly	1	2	3	4 5
20	Doing things with relatives (get-togethers, dinners, etc.).	1	2	3	4 5
21	Seeking professional counselling and help for family difficulties.	1	2	3	4 5
22	Believing we can handle our own problems.	1	2	3	4 5
23	Participating in church activities.	1	2	3	4 5
24	Defining the family problems in a more positive way so that we do not become too discouraged.	1	2	3	4 5
25	Asking relatives how they feel about problems we face.	1	2	3	4 5
26	Feeling that no matter what we do to prepare, we will have difficulty handling problems.	1	2	3	4 5
27	Seeking advice from a minister.	1	2	3	4 5
28	Believing if we wait long enough, the problem will go away.	1	2	3	4 5
29	Sharing problems with neighbours.	1	2	3	4 5
30	Having faith in God.	1	2	3	4 5

Appendix F: Connor-Davidson Resilience Scale (CD-RISC 10)

(0 = never; 4 = almost always)

	Item	Scale
1	Adapt to change	0 1 2 3 4
2	Can deal with whatever comes	0 1 2 3 4
3	Tries to see humorous side of problems	0 1 2 3 4
4	Coping with stress can strengthen me	0 1 2 3 4
5	Tend to bounce back after illness or hardship	0 1 2 3 4
6	Can achieve goals despite obstacles	0 1 2 3 4
7	Can stay focused under pressure	0 1 2 3 4
8	Not easily discouraged by failure	0 1 2 3 4
9	Thinks of self as a strong person	0 1 2 3 4
10	Can handle unpleasant feelings	0 1 2 3 4

Appendix G: Sociodemographic Sheet, Parents

Sociodemographic sheet for immigrant parents			
•	Parents' gender:	1. Mother 2. Father	
•	Age:	1. 20-30 years old 2. 31-40 years old 3. 41-50 years old 4. >51 years old	
•	Nationality at birth:	1. Scottish 2. Chinese 3. Italian 4. German 5. Indian 6. Lebanese 7. Iraqi 8. Afghanistan 9. Syrian 10. Greek 11. other specify -----	
•	Religion:	1. Christian 2. Muslim 3. Hindu 4. Jewish 5. No religion 6. Other specify -----	
•	Language:	1. Mandarin 2. Arabic 3. Italian 4. Dari 5. Hindi 6. Other specify -----	
•	Educational level:	1. University or higher 2. College 3. High school 4. Primary school 5. No education	
•	Relationship status:	1. Single 2. Married 3. Divorced 4. others:	
•	Employment status:	1. Employed 2. Unemployed 3. Retired	
•	Monthly Household income:	1. < 5000 AU 2. 5000-10.000 AU 3. > 10.000 AU	
•	Number of children:	1. 1-3 2. 4-6 3. > 6	
•	Immigration period:	1. 0-5 years 2. 6-10 years 3. > 10	
•	Child with disability's diagnosis:	_____	
•	Child's gender:	1. Male 2. Female	
•	Child's age:	1. 0-5 Years 2. 6-10 years 3. 11-15 years 4. 15-18 years	

Spouse/partner information:

- **Age:** 1. 20-30 years old 2. 31-40 years old 3. 41-50 years old
4. >51 years old

-
- **Nationality:** 1. Scottish 2. Chinese 3. Italian 4. German 5. Indian
6. Lebanese 7. Iraqi 8. Afghanistan 9. Syrian
10. Greek 11. other specify -----

-
- **Religion:** 1. Christian 2. Muslim 3. Hindu 4. Jewish
5. No religion 6. Other specify -----

-
- **Language:** 1. Mandarin 2. Arabic 3. Italian 4. Dari
5. Hindi 6. Other specify -----

-
- **Educational level:** 1. University or higher 2. College 3. High school
4. Primary school 5. No education

-
- **Employment status:** 1. Employed 2. Unemployed 3. Retired.

-
- **Does the family have close family and/or friends support** such as grandmother,
grandfather, aunt, uncle, & etc,,: 1. Yes 2. No

-
- **The family attend the support services in the past or present:**
1. Yes (frequency & duration) 2. No
-

Appendix H: Information Sheet, Organisations



Principal investigator: Professor Sally Chan
Dean of Nursing, Head of School, Nursing and Midwifery
Richardson Wing
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NSW 2308 AUSTRALIA
Telephone: +61 2 49216770
Email: sally.chan@newcastle.edu.au
Web: <http://www.newcastle.edu.au>

Organisational Information Statement for the Research Project:

Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A mixed Methods Study

Your organisation has been invited to participate in the research project identified above which is being conducted by the researcher listed at the end of this statement from the school of nursing at the University of Newcastle. The research is a part of Ethar Alsharaydeh's studies at the University of Newcastle, supervised by professor Sally Chan from the school of nursing at the University of Newcastle.

Why is the research being done?

The purpose of the research is to examine the relationship between burdens, coping, and resilience of immigrant parents raising disabled child. We want find out immigrant parents' everyday burdens, how they overcome their burdens, and what are the factors that help them to be resilient from the perspective of the parents and perspectives of service providers. This information will help us to provide more relevant support and successful help in future.

Who can participate in the research?

Your organisation has been invited to participate in this study because it is an organisation that provide care and empower families raising children with disabilities from different cultural background living in Australia.

What would your organisation be asked to do?

If your organisation participates in the study, it will be asked to facilitate recruitment of immigrant parents raising children with disabilities (clients). You will provide the researcher of the list of activities and meetings that will be held by your organisation for the immigrant parents to help the researcher to approach the meetings and promote her study.

If your organisation participates in the study, it will be asked to facilitate recruitment of the organisation's case managers and coordinators to participate in interview phase of this study. The

researcher will approach the organisation centres and will recruit eligible case managers and coordinators for the interview. The student researcher Ethar Alsharaydeh will conduct the interviews.

What choice do your clients and service providers have?

Participation in this research is entirely participants' choice. Only immigrant parents and case managers or coordinators who give their informed consent will be included in the project. Whether or not participants decide to participate, their decision will not disadvantage them. If immigrant parents do decide to participate, they may withdraw from the project at any time prior to submitting their completed survey or finishing interview. Please note that due to the anonymous nature of the survey, immigrant parents will not be able to withdraw their response after it has been submitted.

In interview phase, immigrant parents and case managers or coordinators may withdraw from the project at any time.

How much time will it take?

This study will start in 01/09/2018 and finish in 01/09/2019.

What are the risks and benefits of participating?

Risks

There are no anticipated risks associated with participating in this research.

Benefits

Whilst there are no anticipated benefits to your organisation in participating in this research, the findings will help to improve services provided to immigrant parents with disabled children in the future. The findings of this study will provide new evidence for service planners and providers to plan relevant and effective services for new immigrant parents especially for those caring for children with disabilities.

How will participants' privacy be protected?

Data will be retained for at least 5 years at the University of Newcastle's ownCloud secure server. Hard copy surveys will be stored in a locked filing cabinet in the Chief Investigator's office. Audio recordings will be stored on the University of Newcastle's ownCloud secure server, research assistant will sign a confidentiality agreement for the transcribing of the interview data, data will be securely destroyed in line with UON policy provisions for research conducted by University staff.

All the information collected from the participants for the study will be treated confidentially, and only the researchers named at the end of this statement and research staff will have access to it. If the participants decide to withdraw, all the information relating to them will also be withdrawn from the study.

The interview sessions will be audio recorded to be transcribed soon after. All identifying information will be kept confidential. At the time of the recording, any identifying information will be replaced by a numbered code. The transcribed interview may be used in future studies; however, participants will not be identified at any stage of data analysis or in the reporting of the results. We expect the results to be published in scientific journals, and presented at conferences.

How will the information collected be used?

The collected data will contribute towards Ethar Alsharaydeh's PhD thesis and may be presented in academic publications, journals or conferences. Non-identifiable data may be also shared with other parties to encourage scientific scrutiny and to contribute to further research and public knowledge, or as required by law.

At the end of study, the researcher will provide your organisation of a report discussed all the findings of this study.

What do your organisation need to do to participate?

The centre manager will be advised to read this Information Statement and be sure he/she understand its contents before provide consent to participate. If there is anything you do not understand, or you have questions, you will be advised to contact the researcher.

Further information

If you would like further information, you will be advised to contact Professor Sally Chan. She will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, you will be advised to feel free to contact any of the investigators listed at this document.

Thank you for considering this invitation.

Name (Chief Investigator)

Name (Student researcher)

Signature

Signature

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2018-0283.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.

Research Contact Information

Co- investigators and Contact Details:

Professor Regina Lee

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This information sheet is for you to keep

Appendix I: Consent Form, Organisations



Principal investigator: Professor Sally Chan
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Web: <http://www.newcastle.edu.au>

Consent Form for the Research Project:

Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A mixed Methods Study

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which the organisation has retained.

I understand that organisation's clients (immigrant families) and service providers can withdraw from the project at any time and do not have to give any reason for withdrawing.

Please tick the box/boxes of the activities that you agree to participate in this research project.

The organisation consent to:

- ☐ facilitate immigrant parents recruitment;
- ☐ facilitate service providers recruitment.

I understand that personal information of the organisation's clients and service providers will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: _____

Designation: _____

Signature: _____

Date: _____

Appendix J: Poster, Parents

BURDENS, CHALLENGES, COPING AND RESILIENCE IN CARING FOR A CHILD WITH DISABILITY AMONG IMMIGRANT PARENTS



Are you an immigrant mother or father raising a child with disability? We would like you to help us.

We are seeking participants who would like to contribute to our research project. This project aims to examine burdens, coping, and resilience of immigrant parents raising disabled child.



For more information about the project please contact:

Ethar Alsharaydeh

PhD candidate, School of Nursing and Midwifery

The University of Newcastle

Email: ethar.alsharaydeh@uon.edu.au

Tel: 0415065782

Project supervisors:

Professor Sally Chan, (02) 49216770

Professor Regina Lee, (02) 4921 5768

Dr. Muhammad Alqudah, (02) 49854455

This project has been approved by the University of Newcastle Human Research Ethics Committee, HREC Approval No. H-2018-0283.

Appendix K: Information Sheet, Parents



Principal investigator: Professor Sally Chan
Dean of Nursing, Head of School, Nursing and Midwifery
Richardson Wing

University Drive
Callaghan
NSW 2308 AUSTRALIA
Telephone: +61 2 49216770
Email: sally.chan@newcastle.edu.au
Web: <http://www.newcastle.edu.au>

Information Statement for the Research Project:

Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A mixed Methods Study

You are invited to participate in the research project identified above which is being conducted by the researcher listed at the end of this statement from the school of nursing at the University of Newcastle. The research is part of Ethar Alsharaydeh's studies at the University of Newcastle, supervised by professor Sally Chan from the school of nursing at the University of Newcastle.

Why is the research being done?

The purpose of the research is to examine the relationship between burdens, coping, and resilience of immigrant parents raising a disabled child. We want find out your everyday burdens, how you overcome your burdens, and what are the factors that help you to withstand or recover quickly from difficult conditions so we can provide more relevant support and successful help in future.

Who can participate in the research?

You are being invited to participate in this study because you are 1) mothers or/and fathers who are immigrated from their country of birth to settle in Australia 2) having a child or more with one or more developmental disabilities (has to be diagnosed by the medical health profession) 3) having below 18 years old disabled child and 4) who are able to read, speak or understand basic English (fifth grade level).

Please note that you are ineligible to participate if you 1) you are not immigrant 2) do not have a child with disability or have over 18 years old adult with developmental disabilities or 3) you are not able to read, speak, or understand basic English (below fifth grade level)".

You are being invited to participate in this study since your child is receiving support from National Disability Insurance Scheme (NDIS) and you will be contacted through them.

What would you be asked to do?

If you agree to participate, you will be asked to complete a questionnaire survey asking about your burdens in your experience of raising a disabled child, how you are coping with care giving and factors that help you to adapt well. We will ask for some demographic information such as your age, however all data analysis will be anonymous. Survey will be held at a time and location convenient to you. You have the choice to complete the survey in the NDIS centre or at home. If you complete the survey in the centre it will be collected later by the researcher. If you choose to complete the survey at home, you will be able to send it to the researcher using the prepaid envelope provided with the survey within two weeks.

Following phase one data collection, you will be invited to face-to-face interview on your experience of raising a child with disability. During the meeting you will be asked to tell us about your experience in providing care for your disabled child. The conversation will be audio recorded and transcribed soon after the meeting. At any time during the interview you may ask for the recording to be stopped and have sections of it erased and you may be approach to discuss the analysis. At the time of the interview we will give your recording a numbered code to replace your name and any other identifying information. The meeting is an opportunity for us to learn about your experiences with providing care for your disabled child. Interviews will be held in NDIS centre at a time convenient to you. The student researcher Ethar Alsharaydeh will conduct the interviews. Survey and interview will occur on two separate days.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. If you do decide to participate, you may withdraw from the project at any time prior to submitting your completed survey. Please note that due to the anonymous nature of the survey, you will not be able to withdraw your response after it has been submitted.

How much time will it take?

The survey should take about 30 minutes to complete. If you participate in the interview, the one-on-one interview should take about one hour.

What are the risks and benefits of participating?

Risks

Some of the questions deal with potentially sensitive issues such as your experience of raising child with disability. Should you find any of the questions upsetting you can skip the question or stop your participation at any time. We can help you contact your case manager immediately. You can also contact Lifeline on 131114 if you wish to seek support regarding any of the issues raised within the survey or interview. The researcher will provide information on counselling services available if you require.

Benefits

Whilst there are no anticipated benefits to you personally in participating in this research, the findings will help to improve services provided to immigrant parents with disabled children in the future. The findings of this study will provide new evidence for service planners and providers to plan relevant and effective services for new immigrant parents especially for those caring for children with disabilities.

How will your privacy be protected?

Data will be retained for at least 5 years at the University of Newcastle's ownCloud secure server. Hard copy surveys will be stored in a locked filing cabinet in the Chief Investigator's office. Audio recordings will be stored on the University of Newcastle's ownCloud secure server, research assistant

will sign a confidentiality agreement for the transcribing of the interview data, data will be securely destroyed in line with UON policy provisions for research conducted by University staff.

All the information collected from you for the study will be treated confidentially, and only the researchers named at the end of this statement and research staff will have access to it. If you decide to withdraw, all the information relating to you will also be withdrawn from the study.

The interview sessions will be audio recorded to be transcribed soon after. All identifying information will be kept confidential. At the time of the recording, any identifying information will be replaced by a numbered code. The transcribed interview may be used in future studies; however, you will not be identified at any stage of data analysis or in the reporting of the results. We expect the results to be published in scientific journals and presented at conferences.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

How will the information collected be used?

The collected data will contribute towards Ethar Alsharaydeh's PhD thesis and may be presented in academic publications, journals or conferences. Non-identifiable data may be also shared with other parties to encourage scientific scrutiny and to contribute to further research and public knowledge, or as required by law.

If you would like a copy of the summary of the results, please email the Chief Investigator : sally.chan@newcastle.edu.au after 30/12/2019 and she will send you a report of the research findings.

Individual participants will not be named or identified in any reports arising from the project although individual anonymous responses may be quoted. Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact the researcher.

If you would like to participate, please sign the consent form provided by the researcher and provide your consent if you would like to participate in survey phase only or in survey and interview phases.

If you would you like to participate in survey phase, please complete and return the attached anonymous questionnaire to the researcher OR drop the survey in the sealed box that placed by the researcher in the NDIS centre OR post it using the pre-paid envelope provided.

If you would like to participate in interview phase too, please provide your contact details on the consent form and the researcher will contact you to arrange time and date to conduct the interview in the NDIS centre.

Further information

If you would like further information, please contact Professor Sally Chan. She will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact any of the investigators listed at this document.

Thank you for considering this invitation.

Name (Chief Investigator)

Name (Student researcher)

Signature

Signature

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2018-0283.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.

Research Contact Information

Co- investigators and Contact Details:

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This information sheet is for you to keep

Appendix L: Consent Form, Parents



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Web: <http://www.newcastle.edu.au>

Consent Form for the Research Project:

Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A mixed Methods Study

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

Please tick the box/boxes of the activities that you agree to participate in this research project.

I consent to:

- ☐ complete a questionnaire;
- ☐ participate in an interview.

I understand that my personal information will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: _____

To participate in the further interview after the questionnaire survey I can be contacted by:

Tel: (Home) _____ (Mobile) _____

Email address _____

Postal address: _____

Other ways of contact: _____

Signature _____ Date: _____

Appendix M: Poster, Service Providers

BURDENS, CHALLENGES, COPING AND RESILIENCE IN CARING FOR A CHILD WITH DISABILITY AMONG IMMIGRANT PARENTS



**Are you a case manager or coordinator who engaged working with immigrant families raising a child with disability?
We would like you to help us.**

We are seeking participants who would like to contribute to our research project. This project aims to examine burdens, coping, and resilience of immigrant parents raising disabled child.



For more information about the project please contact:

Ethar Alsharaydeh

PhD candidate, School of Nursing and Midwifery

The University of Newcastle

Email: ethar.alsharaydeh@uon.edu.au

Tel: 0415065782

Project supervisors:

Professor Sally Chan, (02) 49216770

Professor Regina Lee, (02) 4921 5768

Dr. Muhammad Alqudah, (02) 49854455

This project has been approved by the University of Newcastle Human Research Ethics Committee, HREC Approval No. H-2018-0283.

Appendix N: Information Sheet, Service Providers



Principal investigator: Professor Sally Chan

Dean of Nursing, Head of School, Nursing and Midwifery

Richardson Wing

University Drive
Callaghan
NSW 2308 AUSTRALIA
Telephone: +61 2 49216770
Email: sally.chan@newcastle.edu.au
Web: <http://www.newcastle.edu.au>

Information Statement for the Research Project:

Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A mixed Methods Study

You are invited to participate in the research project identified above which being conducted by the researcher is listed at the end of this statement from the school of nursing at the University of Newcastle. The research is part of Ethar Alsharaydeh's studies at the University of Newcastle, supervised by Professor Sally Chan from the school of nursing at the University of Newcastle.

Why is the research being done?

The purpose of the research is to examine the relationship between burdens, coping, and resilience of immigrant parents raising disabled child. We want find out immigrant parents' everyday burdens, how they overcome their burdens, and what are the factors that help them to be resilient from the perspective of service providers. This information will help us to provide more relevant support and successful help in future.

Who can participate in the research?

You are being invited to participate in this study because you are a service provider who 1) engaged working as case manager or coordinator in NDIS for at least 12 months and 2) willing to participate in the interview.

Please you are ineligible if you are service providers who are working in senior management such as office workers and who do not have face-to-face contact with immigrant parents.

What would you be asked to do?

If you agree to participate, you will be invited to a face-to-face or a telephone interview. You will be asked to share with us your perspective of parental burdens among immigrant parents in providing care for their disabled child and how they cope with caregiving experience.

We will ask also for demographic information such as your age, gender, and nationality at birth. The interview will be conducted at a time that is convenient to you. The conversation will be audio recorded and transcribed for analysis. You will be given the option to review the recording and/or transcript of your interview to confirm your contribution. During the interview you can stop at any time or ask for recording to be erased and you may be approached to discuss the analysis. The student researcher Ethar Alsharaydeh will conduct the interviews.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. If you do decide to participate, you may withdraw from the project at any time.

How much time will it take?

The one-on-one interview will take about one hour

What are the risks and benefits of participating?

Risks

There are no anticipated risks associated with participating in this research.

Benefits

Whilst there are no anticipated benefits to you personally in participating in this research, the findings will help to improve services provided to immigrant parents with disabled children in the future. The findings of this study will provide new evidence for service planners and providers to plan relevant and effective services for new immigrant parents especially for those caring for children with disabilities.

How will your privacy be protected?

Data will be retained for at least 5 years at the University of Newcastle's ownCloud secure server. Audio recordings will be stored on the University of Newcastle's ownCloud secure server, research assistant will sign a confidentiality agreement for the transcribing of the interview data, data will be securely destroyed in line with UON policy provisions for research conducted by University staff.

All the information collected from you for the study will be treated confidentially, and only the researchers named at the end of this statement and research staff will have access to it. If you decide to withdraw, all the information relating to you will also be withdrawn from the study.

The interview sessions will be audio recorded to be transcribed soon after. All identifying information will be kept confidential. At the time of the recording, any identifying information will be replaced by a numbered code. The transcribed interview may be used in future studies; however, you will not be identified at any stage of data analysis or in the reporting of the results. We expect the results to be published in scientific journals and presented at conferences.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

How will the information collected be used?

The collected data will contribute towards Ethar Alsharaydeh's PhD thesis and may be presented in academic publications, journals or conferences. Individual participants will not be named or identified in any reports arising from the project although individual anonymous responses may be quoted. Non-identifiable data may be also shared with other parties to encourage scientific scrutiny and to contribute to further research and public knowledge, or as required by law.

If you would like a copy of the summary of the results, please email the Chief Investigator: sally.chan@newcastle.edu.au after 30/06/2019 and she will send you a report of the research findings.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact the researcher.

If you would like to participate, please sign and return the consent for interview document. The researcher will contact you to arrange time and date to meet in NDIS centre to conduct the interview face-to-face or via phone.

Further information

If you would like further information, please contact Professor Sally Chan. She will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact any of the investigators listed at this document.

Thank you for considering this invitation.

Name (Chief Investigator)

Name (Student researcher)

Signature

Signature)

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2018-0283.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.

Research Contact Information

Co- investigators and Contact Details:

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This information sheet is for you to keep

Appendix O: Sociodemographic Sheet, Service Providers

Sociodemographic sheet for service providers			
•	Service provider's gender: 1. Male 2. Female		
•	Age: 1. 20-30 years old 2. 31-40 years old 3. 41-50 years old 4. >51 years old		
•	Nationality at birth: 1. Scottish 2. Chinese 3. Italian 4. German 5. Indian 6. Lebanese 7. Iraqi 8. Afghanistan 9. Syrian 10. Greek 11. other specify -----		
•	If you are not born in Australia, how long have you been in Australia? _____ _____		
•	Ethnicity _____		
•	Religion: 1. Christian 2. Muslim 3. Hindu 4. Jewish 5. No religion 6. Other specify -----		
•	Position designation in your institution _____		
•	Years of experience in your institution _____		

Appendix P: Consent Form, Service Providers



Principal investigator: Professor Sally Chan

Dean of Nursing, Head of School, Nursing and Midwifery

Richardson Wing

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NSW 2308 AUSTRALIA
Telephone: +61 2 49216770
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Web: <http://www.newcastle.edu.au>

Consent Form for the Research Project:

Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A mixed Methods Study

I agree to participate in the interview of the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time, and do not have to give any reason for withdrawing.

I understand that my personal information will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: _____

Contact phone number: _____

Signature: _____

Date: _____

Appendix Q: Sample Transcript

Full transcript and coding for Emmy (parent number 7)	
Transcription	Codes
<p>Q: Hi Mrs Emmy, how are you today?</p> <p>A: I am good thank you.</p> <p>Q: Could you please introduce yourself?</p> <p>A: My name is Emmy. I came from Bangladesh. We married and migrated here, when we were young, in 1995, 24 years ago.</p> <p>I have a daughter with Autism, she was born in 1997.</p> <p>Q: Can you please tell me What are the everyday challenges that you experience when raising a child with a disability in Australia?</p> <p>Could you please tell me about your experience in providing care for a child with a disability?</p> <p>A: It was difficult. Particularly when I was studying, at that time preparing for becoming a doctor here. I had 2 children. Lots of sacrifice and lot of hard works. I have to say without the help of my husband I would not be here. Even I would not have the kids the way we brought them up.</p> <p>No other family members were here and, no support from them, we had to do all by ourselves.</p> <p>During that time, all my times, I was studying, going to the hospitals, taking the preparation for the clinical exams. But he (husband) was the one, who looked after the kids. I had a boy older than her. They are 14 and half months apart. So, 2 little ones and I was a student. He (husband) was working, full time work. So, he had to take time for her and then I sit for the exam. That is how we managed.</p> <p>Q: Could you please describe the impact of caring for a child with a disability on your life after immigration?</p> <p>A: yes, I have some difficulties in my social life but we tried to manage it. Because we know that we have</p>	<p>Receive spouse support</p> <p>Lack of extended family support</p> <p>Have busy life</p> <p>Lack of friends' support</p>

<p>a sick child and we need to adjust according to her needs and our needs. We have to come in the middle of somewhere that we also fulfil our need in some parts and her need in some parts. We deal with our friends, who accepts us. For sure not all families accept us as we do have a child with disability. If someone does not like my child, I do not even go near them. I am not going for a place where I feel unwelcomed. I stay home. Because there is no point. I will only accept the friends, who accept my daughter. That is the why we always dealt. I do not think there are many who did not like us that is the positive thing. Whether he is Australian or non-Australians, does not matter, everybody loves us I think. The acceptance of a sick child in this time is great. Everybody knows that sick child what you can do, just look after her. Sometimes I tell my friends that I have a sick child and you have to look after. But not always go well.</p> <p>Q: Could you please tell me about your experience in raising a child with a disability in Australia which has a different language and culture from your homeland?</p> <p>A: In Australia, I mean the Australian people, are accepting it. People understand more than, say, 30 years ago. I am lucky that I gave birth of a sick child in a western country and at this time. Because people know, there are sick people. There are people will not accept it, but I pay attention to people who are accepting my daughter. And, Alhamdulillah we are born Muslim. Islam is the acceptance of everything. Also we do not feel it difficult. Actually, it is difficult, but we believe that if we can do (manage) it successfully in this world, we will be successful in the next life. This is our hope. That is why we do not get devastated, and frustrated. We never asked why we have this child. We never asked, because we know that there is a reason behind it. Allah give you something that you can carry. Allah will not give you a burden. Allah knows our strength that we can do it.</p> <p>Q: What is the impact of living away from extended family? How does it impact your experience in raising your child with a disability in Australia?</p> <p>?</p>	<p>The Australian culture accepted disability</p> <p>Faith is a source of coping</p>
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<p>A: Look I told you, I do not have any extended family in Australia. My husband and my son help me. We as a family manage to help ourselves. I will give you an example: My son is less than one year and half older than her. He has been always very caring since he was little. He always looked after her. Because she did not know where she was going. If we went to any party or somewhere, he is one who looking after her where she is going. All of our friends asks us how your son caring your daughter. Then, I have another daughter, who is 6 years younger than our that daughter. She is same caring to her. We made the environment in our family that this is part of our life, this is our journey and this is how we do. We never our sick daughter from anything, like,</p>	<p>Received spouse and son support</p>
<p>if there is a wedding her couples will go, in that case we do not go. People do not invite us only as a couple. In my life in Australia, only one invitation was such, where the couples were invited and we did not attend. Because my priority is my daughter, my child. Our culture is different, we are always invited as a family. I never accepted any invitation (as a couple). even I've live for long time here but I can't understand this culture in this matter. How they invite only the couples, what about the kids??</p>	<p>Culture different from homeland + social isolation</p>
<p>Now they (children) have grown older. They can stay home. My son is 23 this year and my other daughter is 15. So, they can look after (her). We can leave them at home (if it is necessary).</p>	
<p>For the language, it is not a barrier. I came to Australia for study and worked here. It was not a problem. Even in Bangladesh it was not a problem. I studied in English schools and before coming here in Australia, I lived in England. So, language was not a barrier.</p>	<p>Language is not a barrier</p>
<p>For the culture, we are in Islamic culture, but we are moderate. We accepted everything. Actually, we do not hate the other culture and we do not accept the western culture totally, we are in between. The other (western) cultures do not deny us and we do not deny them, so, we are at the middle.</p>	<p>Culture in general in not a barrier</p>
<p>I don't know vast about my culture. Because I came left my country and came here at young age. Then all</p>	

<p>the kids brought up here. I think, I know this culture more than I know my culture.</p> <p>Q: Could you please share your experience in utilising healthcare and educational systems in Australia?</p> <p>A: Being a doctor made it easier for us. Because, I am a doctor, if any appointment needed I will organize and all my colleagues help about it. I think that is the biggest thing, which made it easier for us as I am a doctor.</p> <p>When I look at the other people, I need to advocate the people who are in need, they are not professional like me, they are not working in this country, they do not have personal ability to take a burden like this, so for them I see that they do not get enough services and support. So the people who need, they are delayed to get the support, that is what I see, there is a long waiting time for the government approval. Even if they get approval sometimes there are not enough service. This is what I see with my patients.</p> <p>Q: How about the educational system, because she enrolled in some special sessions or schools, any challenges to navigate the educational system?</p> <p>A: That is, I think my husband knows better. Because, he takes them to school and deals with the schools, teacher and everyone there. I think, there will be a little bit here and there but nothing major.</p> <p>Q: What made these challenges harder/easier?</p> <p>A: I think, we came early at the young age, we knew the culture ahead, although we are looking a bit different from them but we understand them. That is why they accept us and consider us as a part of their community and part of their people. That makes things easy.</p> <p>Look I believe what make me cope well that I always I am positive. See the full half of the cup. I always look in the positive things and the negative things I just put them behind. That is I think, the best way to deal with any problem. If there is a problem in life, not only a sick child, you need to think about what is</p>	<p>Being a doctor make navigating healthcare system easy</p> <p>Lack of healthcare support</p> <p>Long immigration period makes challenges easier</p> <p>Positive perspective in life lighten the challenges</p>
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<p>positive in that problem and make a negative to positive. Then you will not feel frustrated, or hard and then it is not challenging. Because you can make it easy.</p> <p>Sometimes, probably, things might seem a little bit hard but we do not put any stress on it. We let it go. You know, if anything is hard and I think it hard, then it makes life difficult. But if anything is difficult but we think let us make it a bit easy, eliminate some difficult things and bring some easy things. I think, we do not stress too much.</p> <p>Q: How do you cope to overcome your challenges?</p> <p>A: When she was first diagnosed, devastating. I did not accept. Because there was no-one in the family diagnosed with autism, so it was really difficult to accept. But once we accepted, I think again it came from our religion, that He is one who's given you this and it is my child. I cannot let anyone handle it. It is my job. It is my daughter and I think that gave me the strength. Allah made it easy. I think, if you leave it to Allah that Ya Allah, you have given it to me, now give me strength. Then, he will give you the strength.</p> <p>Q: What do you think that facilitate your coping?</p> <p>A: Look, also, because I am a doctor I see lots of same patients, and some are even worse. Comparing to see what I have seen in my life, my daughter is much better. Although, she has the autism but I see many patients who have much more difficult situation than me (my child). So, I am glad, Alhamdulillah. She can walk, she can express a little bit of things, she understands, she is happy, she is not in pain. You know, she is not wheelchair bound.</p> <p>I can't deny that being a good English speaker me and my husband made our coping better. We can communicate with people, we can access NDIS and we can ask for our needs.</p> <p>So many positives and I can take her anywhere. She can go and stay in the party. She will make some noise but everyone knows that she is sick. So, if someone do not accept, I say please move. She is my child and I do not think that with anyone I have to do</p>	<p>“take it easy” perspective lighten the challenges</p> <p>Religious beliefs give her the strength</p> <p>Noncomplicated disability facilitate coping</p> <p>English fluency facilitate coping</p>
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<p>that. This is my feeling. Because, if anyone cannot accept my child, this is his problem, not my daughter's problem or my problem. Society has to accept as I accept everyone. So, everyone has to accept mine, because no-one chose to be an autistic child. No-one chose have a sick child. If I can accept everyone and I want to help and this is my aim in life. Thanks God that I am a doctor and my aim as a doctor is to help everyone. Every person comes to me I wish to do something for him.</p> <p>Q: Yeah, that is good, may Allah reward you. A: Thank you. If I have the feeling to help anyone then they do the same thing. People do the same thing and everyone loves me. I cannot say anyone hate me. You saw me in practice, how receptionist, doctors, and everybody loves me in front of me, I do not know what they do behind, but I feel they love me from their heart, wherever I worked. If anywhere people did not like me, I did not go near them. It was rear, but it can happen, I do not need to go to close to them.</p> <p>Q: What do you think that hinder your coping? A: No hindrance. We manage, we manage somehow. We plan and we manage.</p> <p>Q: nothing to mention. A: Nothing to mention, I do not feel problem.</p> <p>Q: What kind of supports and services in this area? A: Support services. See, because I know the systems. For my daughter I can support what she needs and the government support is enough for her. We feel that it is enough. They providing special treatment like speech pathology for my daughter, financial support, Government gives it every fortnight or every month, to be honest NDIS as a disability service is amazing. Helped us a lot.</p> <p>But you know, I can see the families, who don't speak English, they will have lots of difficulties and do not know the system.</p> <p>But, with the interpreter system provided sometimes by NDIS, they are trying their best, it is good. To make it easier.</p>	<p>Expectation of being accepted by others</p> <p>NDIS is an amazing support</p> <p>Language barrier hinder complicated the experience</p> <p>Interpreting service might help</p>
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<p>Q: Anything like any personal view you want to add at the end of this interview?</p> <p>A: It is all right, that Allah has given us. Alhamdulillah.</p> <p>Q: Thank you so much. I appreciate you time. Thank you so much. Much appreciated.</p> <p>A: Thank you.</p>	
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Each response to the interview questions was considered a meaningful unit. The meaningful units were given descriptive codes. The assigned codes were based on broad topical areas consistent with the main aim of this study. The researcher then read within the coded data and created more discrete descriptive subthemes. For example; the codes Lack of **extended family** support, Lack of **friends'** support and Lack of **healthcare** support were showed similarities as lack of social networks. Also, after deep reading of the parents' verbatim, the researcher found that lack of social networks lead parents to feel socially isolated. So, the subtheme was emerged as "Being isolated due to lack of social networks". This subtheme was one of the parental challenges in raising their children with disabilities, thus it was sorted under the theme "Ongoing challenges of everyday life".

Themes	Subthemes	Codes
Ongoing challenges of everyday life	Being isolated due to lack of social networks	<ul style="list-style-type: none"> • Lack of extended family support • lack of friends' support • Lack of healthcare support
	Having difficulty adapting to a new culture	<ul style="list-style-type: none"> • Culture different from homeland • Influence English complicated the experience
Ongoing coping tactics	Seeking spiritual support	<ul style="list-style-type: none"> • Faith is a source of coping • Religious beliefs give her the strength

	Learning how to be optimistic, positive and cheerful	<ul style="list-style-type: none"> • Positive perspective in life lighten the challenges • “take it easy” perspective lighten the challenges
Ongoing help-seeking behaviours	Having English language Skills	<ul style="list-style-type: none"> • English fluency facilitate coping
	Identifying the availability of disability services	<ul style="list-style-type: none"> • NDIS is an amazing support • Interpreting service might help

Appendix R: Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Professor Sally Chan
Cc Co-investigators / Research Students:	Professor Regina Lee Doctor Muhammad Alqudah Ms Ethar Alsharaydeh
Re Protocol:	Burdens, Challenges, Coping and Resilience in Caring for a Child with Disability among Immigrant Parents – A mixed Methods Study
Date:	17-Aug-2018
Reference No:	H-2018-0283
Date of Initial Approval:	17-Aug-2018

Thank you for your **Response to Conditional Approval (minor amendments)** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited** review by the Ethics Administrator.

I am pleased to advise that the decision on your submission is **Approved** effective **17-Aug-2018**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is **H-2018-0283**.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants You may then proceed with the research.

For Noting:

Please ensure all documents are once again reviewed for grammatical errors and omitted words. It is recommended that this review is undertaken before the recruitment process commences.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress, Reporting of Adverse Events*, and *Variations to the Approved Protocol* as detailed below.

PLEASE NOTE:

In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the

University's HREC.

- **Monitoring of Progress**

Other than above, the University is obliged to monitor the progress of research projects involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. A progress report is required on an annual basis. Continuation of your HREC approval for this project is conditional upon receipt, and satisfactory assessment, of annual progress reports. You will be advised when a report is due.

- **Reporting of Adverse Events**

1. It is the responsibility of the person **first named on this Approval Advice** to report adverse events.
2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.
3. Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Approval Advice to the (HREC) by way of the Adverse Event Report form (via RIMS at <https://rims.newcastle.edu.au/login.asp>) within 72 hours of the occurrence of the event or the investigator receiving advice of the event.
4. Serious adverse events are defined as:
 - o Causing death, life threatening or serious disability.
 - o Causing or prolonging hospitalisation.
 - o Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.
 - o Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.
 - o Any other event which might affect the continued ethical acceptability of the project.
5. Reports of adverse events must include:
 - o Participant's study identification number;
 - o date of birth;
 - o date of entry into the study;
 - o treatment arm (if applicable);
 - o date of event;
 - o details of event;
 - o the investigator's opinion as to whether the event is related to the research procedures; and
 - o action taken in response to the event.
6. Adverse events which do not fall within the definition of serious or unexpected, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

- **Variations to approved protocol**

If you wish to change, or deviate from, the approved protocol, you will need to submit an *Application for Variation to Approved Human Research* (via RIMS at <https://rims.newcastle.edu.au/login.asp>). Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. **Variations must be approved by the (HREC) before they are implemented** except when Registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

Linkage of ethics approval to a new Grant

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics

approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

Best wishes for a successful project.

Associate Professor Helen Warren-Forward
Chair, Human Research Ethics Committee

For communications and enquiries:
Human Research Ethics Administration

Research & Innovation Services
Research Integrity Unit
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 17894
Human-Ethics@newcastle.edu.au

RIMS website - <https://RIMS.newcastle.edu.au/login.asp>

Linked University of Newcastle administered funding:

Funding body	Funding project title	First named investigator	Grant Ref
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