Caregiving for individuals with neurodevelopmental disability-influence of implicit attitudes and affiliate stigma on expressed emotions

Nee, Michelle Si Hui

2018

Nee, M. S. H. (2018). Caregiving for individuals with neurodevelopmental disability-influence of implicit attitudes and affiliate stigma on expressed emotions. Master's thesis, Nanyang Technological University, Singapore.

<https://hdl.handle.net/10356/90170>

<https://doi.org/10.32657/10220/47318>

**CAREGIVING FOR INDIVIDUALS WITH NEURODEVELOPMENTAL
DISABILITY- INFLUENCE OF IMPLICIT ATTITUDES AND AFFILIATE STIGMA
ON EXPRESSED EMOTIONS**

MICHELLE NEE SI HUI

School of Social Sciences

A THESIS SUBMITTED TO THE NANYANG TECHNOLOGICAL UNIVERSITY

IN FULFILLMENT OF THE REQUIREMENT FOR THE DEGREE OF

MASTER OF ARTS

2018

ACKNOWLEDGEMENTS

The completion of this dissertation would not have been possible without the kind support and assistance of many who helped in a way or another.

First and foremost, I would like to express my deepest gratitude to my supervisor, Prof Joyce. She has taught me way more than just research skill- the effort she makes in ensuring I truly learn- her dedication and commitment is something I always seek comfort in. Thank you, Prof Joyce, for always making me feel reassured at every step of my graduate school life. Your sweet disposition and ability to manage various aspect of your life is something I aspire to be work towards! No words can truly express my gratitude for you-your hospitality and approachableness certainly makes the life of a graduate research student so much less daunting.

Next, I would like to take the opportunity to thank all my research participants, in particularly all the organizations and caregivers whom acceded to my request. It's not easy, I know, in coming forth to share their caregiving experience in Singapore. Thank you SPARKS, Down Syndrome Association, Ms Gomy of Presbyterian Community Services, Dyslexia Association of Singapore and Annie, admin of the Facebook group. This dissertation can never be completed if not for the willingness of these organization and caregivers in stepping out of their comfort zone to share with me their thoughts and feelings. I am truly indebted to the great hospitality and earnest sharing sessions.

I would also like to take this opportunity to thank all my friends in NTU, especially Kristy, Shirley and Panglab members! Amidst the different research we embarked on, I am forever grateful to have met a strong support group in graduate school. Your valuable input in the sharing sessions we have, and help rendered in any way for my research is truly appreciated. A big shout out to my other friends as well, especially Ruxuan- thanks for always being there.

Lastly, I would like to thank my family for always being there for me and in raising me to be whom I am today. A big thank you to Eugene too, for always enduring the rants and helping in any way possible.

I dedicate this dissertation to all my friends, family as well as all the caregivers of children with special needs in Singapore.

TABLE OF CONTENTS

	Page
ACKNOWLEDGMENTS	ii
TABLE OF CONTENTS	iv
LIST OF TABLES	viii
LIST OF FIGURES	ix
LIST OF APPENDICES	x
ABSTRACT	xi
1. INTRODUCTION	1
1.1 What is implicit attitude?	1
1.2 Prevalence of neurodevelopmental disabilities	3
1.3 Unveiling the role of implicit prejudice on stigma	4
1.4 Significance of implicit prejudice on dyadic interaction between caregivers and individuals with NDD	5
1.5 Research Focus: Implicit Attitudes in Singapore	8
1.6 Research Overview and Research Question	10
1.7 Scope of Research	13
1.8 Outline of Chapters	13

2.	LITERATURE REVIEW	15
2.1.	Theoretical models of stress and coping of caregivers	15
2.2.	The proposed conceptual framework	18
2.3.	Background and Context: Understanding Singapore and Pre-Existing Attitude	19
2.4.	Primary Stressor: Affiliate Stigma and Caregiver Burden	20
2.5.	Secondary role strain	23
2.6.	Secondary intrapsychic strain	23
2.7.	Outcome: Subjective Well-being and Expressed Emotion	24
2.8.	Role of Perceived Social Support	25
2.9.	Behavioural Outcome: Expressed Emotions	26
3.	STUDY 1	27
3.1.	Initial Theoretical Drive and Plan of Overall Research	27
3.2.	Revised Multimethod Research Design	29
3.3.	Participants: Informed laypeople living in Singapore.	30
3.4.	Instruments and Materials	32
3.5.	Procedure and Consent	35
3.6.	Analyses of Data	36
3.7.	Results	37
3.8.	Cluster Analysis Findings	43
3.9.	Brief Discussion	43

4.	STUDY 2	45
4.1	Research Design.	45
4.2	Participants: Primary informal caregivers of NDD living in Singapore.	46
4.3	Instruments	47
4.4	Procedure and Consent	50
4.5	Data Analysis	52
4.6	Trustworthiness of Study	54
4.7	Quantitative results based on interview and survey	56
4.8	Qualitative Findings	60
4.9	Comparison of themes	83
4.10	General Discussion	83

5	GENERAL DISCUSSIONS	87
5.1	Findings for RQ1: How does the attitude of public towards individual with NDD compare with perceived public attitude by caregivers in Singapore?	88
5.2	Findings for RQ 2: What is the relationship among implicit prejudice, affiliate stigma and expressed emotions towards NDD?	90
5.3	Findings for RQ 3: What is the relationship among implicit prejudice, affiliate stigma, mediators (perceived social support, caregiver burden and caregiver's well-being) and expressed emotions towards NDD, as revealed in qualitative interviews with primary caregivers?	91
5.4	Findings for RQ 4: Is there a discrepancy between level of key variables reported (i.e. implicit prejudice, affiliate stigma, expressed emotions) in qualitative interviews and quantitative self-report questionnaire with primary caregivers?	92
5.5	Contributions to literature	93
5.6	Implications for Practice and Policy	95
5.7	Limitations	98
5.8	Recommendations for Future Research	100
5.9	Conclusion	101

LIST OF TABLES

TABLE	Page
1.1 Demographics of public	31
1.2 Descriptive Statistics for scores on 3 scales (<i>N</i> =228)	37
1.3 Logistic regression predicts factor of expressed emotions	38
1.4 Breakdown in organizational types in sample subgroups	51
1.5 Characteristics of caregivers	57
1.6 Descriptive statistics of each variable	59
1.7 Overview of Themes and Sub-Themes	62
1.8 Participants with Discrepancy in Interview Content and Self-report Questionnaire	86

LIST OF FIGURES

FIGURE	Page
1 Conceptual Framework	18
2 Full hypothesised model	29
3 Overview of research design	30
4 Scree plot from the exploratory factor analysis of SADP	40
5 Scree plot from the exploratory factor analysis of Affiliate Stigma Scale	41
6 Scree plot from the exploratory factor analysis of Family Questionnaire	42
7 Illustration of main themes and sub-themes fit in adapted conceptual framework	63

LIST OF APPENDICES

	Page
Appendix 1: Factor Loadings for Exploratory Factor Analysis	123
Appendix 2: Themes identified from caregiver's responses during face to face semi-structured interview	128
Appendix 3: Study 2 approval from Institutional Review Board (IRB)	175
Appendix 4: Consent form and survey questions for Study 1	176
Appendix 5: Study 2 approval from Institutional Review Board (IRB)	186
Appendix 6: Study 2 letter of Indemnity	187
Appendix 7: Study 2 brochure	188
Appendix 8: Study 2 consent form	189
Appendix 9: Study 2 questionnaire	192
Appendix 10: Interview guide	199

Abstract

Focused on the Singapore context, this research investigates informal caregiver's pre-existing attitude as a direct antecedent to affiliate stigma, caregiver burden and expressed emotions towards children with neurodevelopmental disability (NDD). Study 1 was conducted with two aims: a) to understand self-reported public perception towards individuals with NDD and (b) the relationship among key variables of interest (implicit attitudes, affiliate stigma and expressed emotions). Study 2 was conducted among caregivers of individuals with NDD in Singapore through usage of semi-structured interview and questionnaire to understand the (a) direct influence of pre-existing attitudes and affiliate stigma on expressed emotions and (b) indirect influence of pre-existing attitudes and affiliate stigma on quality of caregiving (i.e. caregiver burden, subjective well-being, perceived social support). In general, participants in Study 1 reported positive attitudes towards individuals with NDD. Analysis of interview data from Study 2 extracted five main themes: 1) knowledge of NDD population prior to caregiver role; (2) thoughts about caregiver role and experience of caregiving for NDD; (3) management of various roles played by caregivers in everyday life; (4) interactions with individuals with NDD and self-concept; and (5) understanding Singapore's cultural context and attitude towards NDD population. Among the 21 caregivers in Study 2, 13 caregivers were found to have discrepancies between quantitative and qualitative measures, which suggest possible intrinsic denial of individual's NDD condition. The preliminary findings of this study suggest a need for developing a research agenda to better understand the impact of implicit prejudice and affiliate stigma on expressed emotions.

Keywords: caregivers, stigma, prejudice, expressed emotions, Singapore, neurodevelopmental disability

CHAPTER ONE

INTRODUCTION

1.1. What is implicit attitude?

Implicit attitudes refer to the “introspectively unidentified (or inaccurately identified) traces of past experience that mediate favourable or unfavourable feeling, thought, or action toward social objects.” (Greenwald & Banaji, 1995, p.8). Since Gordon Allport’s (1954) publication of *The Nature of Prejudice*, research in various fields has examined the antecedents and consequences of prejudice. In recent years, the unconscious, automatic activation of negative implicit attitudes, or implicit prejudice, has been looked into extensively within race, gender and disability studies (Beelmann & Heinemann, 2014; Dasgupta, 2013; Dovidio, Hewstone, Glick, & Esses, 2010; Thomas, Vaughn, Doyle, & Bubb, 2014).

Implicit prejudice has been widely investigated, and research has discovered four key ideas related to the phenomenon. The four ideas relate to (a) the unconsciousness of implicit prejudice within individuals, (b) the relatively stable trait of implicit prejudice across an individual’s lifespan, (c) the automatic activation of implicit prejudice (Crosby, Bromley, & Saxe, 1980; Page, 1997), and (d) the limited effectiveness of implicit prejudice to be eradicated within an individual. In fact, social experiments conducted using brain imaging techniques and time-based assessment have unveiled the continual influence of unconscious attitudes in everyday life, such as subtle behaviours and gestures (i.e., staring, social distance in public), despite one’s effort to suppress biased thoughts (Banaji, Hardin, & Rothman, 1993; Dovidio, Kawakami, & Gaertner, 2002; Fazio, Jackson, Dunton, & Williams 1995; Gaertner & McLaughlin, 1983; Greenwald, McGhee, & Schwartz, 1998; Nosek, Banaji, & Greenwald, 2002).

Currently, few studies within the field of neurodevelopmental disabilities (NDD) have examined how unpaid caregivers' (i.e. family member) implicit attitudes about NDD influence the dynamics of caregiving for individuals with NDD. One possible reason for this lack of research could be society's view of how caregivers should be nurturing providers for the child (American Psychological Association, n.d.). The implication of this societal norm is that it is not acceptable to acknowledge one's negative attitudes, prejudices or beliefs about children or other vulnerable individuals (Anderson, 2011).

Given such societal taboos in place regarding the expression of prejudice towards children, as well as the nature of implicit prejudice being unconscious, it is unlikely that caregivers are aware of their implicit prejudices about disabilities, especially if they are not given the chance to evaluate their beliefs and value systems. For caregivers who knew about implicit prejudice within them and conform to societal norms about caregiver role, they may engage in conscious repression of implicit prejudice about NDD population. However, the automatic process of implicit prejudice may suggest minimal successful conscious repression by caregivers.

According to Yura (1983), parents of children with NDD must understand themselves, the parenting strategies and resources that are needed to raise their child, and facilitate their child's outlook of life. The caregiver's awareness of their level of implicit prejudice towards NDD population is pertinent to their self-understanding. In turn, this self-knowledge and understanding would affect how implicit prejudice affects the quality of care for individuals with NDD.

In understanding how the public perceive individuals with NDD, caregivers can assess to see if their self-understanding about the public aligns. A discrepancy between self-understanding of public and actual public perception could indicate the presence of other factors, including implicit prejudice.

Hence, this research addresses two key questions: (1) How does the attitude of public towards individuals with NDD compare with perceived public attitude by caregivers? (2) Do pre-existing implicit attitudes of caregivers about NDD affect the quality of caregiving experience and interaction with the child? Specifically, Study 1 will address question 1 and Study 2 will address both questions 1 and 2.

Next, we turn our attention to the four important concepts around which this thesis revolved around; neurodevelopmental disabilities, implicit prejudice and stigma; implicit prejudice and expressed emotions; implicit prejudice in Singapore.

1.2. Prevalence of neurodevelopmental disabilities

Neurodevelopmental disabilities (NDD) refer to conditions of lifelong mental or physical impairment before the age of 22 (American Association on Intellectual and Developmental Disabilities, 2016; SPD, 2014). NDD conditions are usually characterised by disruptions in “personal, social, academic, or occupational functioning” (American Psychiatric Association, 2013). Typical examples of NDD conditions include attention-deficit/hyperactivity disorder (ADHD), Down syndrome, autism spectrum disorder (ASD), epilepsy, cerebral palsy, speech and language delays, behavioural problems and global developmental delay (Ministry of Health, 2016; National Center on Birth Defects and Developmental Disabilities, 2015; SPD, 2014).

In recent years, developed nations have seen an increased prevalence of children diagnosed with NDD. For instance, Boyle et al. (2011) reported a 17.1% increase in children diagnosed with NDD from 1997-2008 in xx country. Similarly, Singapore reported a 60% increase in children diagnosed with NDD from 2010 to 2015 (Ministry of Health as cited in Tan, 2016).

Consistent with the growing prevalence of NDD, the increase in research fund allocation to NDD has promoted interest in NDD-related research (Bishop, 2010). Between

2012 and 2014, a total of 2260 NDD-related empirical research were produced (Dykens, 2015). However, only 3% of these studies focused on caregivers. Among these studies, three prominent research areas can be observed. Specifically, research on caregivers of children with DD has extensively investigated the (1) antecedents (i.e., sociodemographic factors) and consequences (i.e., stress, caregiver burden, subjective well-being) of caregiving after child diagnosis, (2) the effectiveness of coping/intervention strategies in moderating or mediating stress of caregiving, and (3) the impact of stigma on caregiver psychological health (i.e., self-esteem and subjective well-being) and caregiver-NDD patient dyadic interaction.

1.3. Unveiling the role of implicit prejudice on stigma

Stigma describes prejudicial attitudes, negative stereotypes, and discrimination targeting a subgroup (Corrigan, 2000; Mukolo et al., 2010). Often, individuals who are stigmatised find themselves being labelled, stereotyped and are faced with status loss and discrimination by others (Corrigan, 2000; Link & Phelan, 2001).

As mentioned previously, individuals with NDD are characterised by mental impairment that may or may not be accompanied by physical impairment. However, because the impairments experienced by individuals with NDD are primarily mental, rather than physical, they tend to be “invisible” in the sense that one could not easily ascertain the true degree of the impairment through casual observation. These “invisible” characteristics of the NDD condition often increase misconception of NDD’s behavioural symptoms as “misbehaviours”. For instance, Gray (1993) noted how some stigmatizing experiences of ASD occurred due to the normal appearance of children with ASD.

Since a child with NDD is greatly dependent on their caregivers, the child’s “misbehaviour” could partially be attributed to caregivers, thereby increasing the likelihood of stigma by strangers towards both the caregivers as well as the individuals with NDD. In fact, research has found that the attribution of blame on caregivers for NDD’s disobedience

resulted in caregivers' reported feelings of shame and worthlessness (Gray, 1993, 2002; Power, 2008; Ryan, 2005; Todd & Shearn, 1997). Additionally, caregivers of NDD are more likely to report affiliate stigma, which refers to the internalization of negative perceptions attributed to child with developmental disability (Mak & Cheung, 2008). When caregivers have internalized the popular stigmatizing notions of what it means to have a disability, these notions become personally relevant to their lives and can result in lower subjective well-being (Link, Cullen, Struening, Shrout & Dohrenwend, 1989; Link & Phelan, 2001; Panier Bagat, & Sasso, 1995; Rosenfield & Wenzel 1997; Ritsher & Phelan, 2004).

Given that stigma and implicit prejudice are two plausible interrelated attitudinal constructs since both hinges on the cognitive, affective and behavioural component of individuals. However, there has been little or no studies that attempt to identify underlying intrapersonal causes of internalized stigma.

1.4. Significance of implicit prejudice on dyadic interaction between caregivers and individuals with NDD

Dyadic interaction refers to the bidirectional exchange between the unpaid caregiver (i.e., family member) and the individual with NDD. According to developmental intergroup theory (Bigler & Liben, 2007), caregivers are crucial in shaping children's attitudes. Through interactions with caregivers, children learn about and emulate emotion regulation techniques for their own social interaction with others (Are & Shaffer, 2016; Ashiabi, 2000; Morris et al., 2011).

Indeed, studies have emphasised that parents' reactions to their child's disability and description of child are related to the level of behavioural problems of the child (Chavira, Lopez, Blacher, & Shapiro, 2000; Kendziora, & O'Leary, 1993). There is also increasing evidence that the social and developmental status of children with cerebral palsy is influenced

by family factors, including the form of parenting that children receive (Plant & Sanders, 2007; Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008).

This emphasises the need for caregivers to realize that children are not ignorant to their surroundings, and that the caregiver-child dyadic relationship is cyclical and dependent on input from both the parent and the child (Phillips-Silver, Aktipis, & Bryant, 2010). Hence, caregivers need to be mindful about both their verbal and more implicit, non-verbal interaction (i.e., body language, word usage, tone) with their children.

In fact, much research has reported that negative parental interactions such as harsh or inconsistent behaviours can predict negative outcomes for children in the long-term (Baumrind, 1967; Deater-Deckard, 1998; Baldry & Farrington 2000; Jackson & Warren, 2000; Mesman & Koot 2000). In another study conducted by Wiegerink, Roebroek, Donkervoort, Stam, and Cohen-Kettenis (2006) on individuals with cerebral palsy, results found that expressed emotions (both overprotection and the negative attitudes) of caregivers may interact with the emotional development of the children.

According to Hastings and Lloyd (2007), expressed emotions consists of two aspects of caregiver's critical comments and the caregiver's emotional over-involvement with the condition of the individual with NDD. Critical comments may be expressed in the form of negative emotions or criticism when asked to describe individuals with NDD. For instance, the daily routine revolving around main caregiver role and other aspects of the caregiver's life may deplete cognitive resources of the caregiver, which in turn results in direct expression of critical comments by the caregiver towards the child with NDD. Emotional over-involvement, on the other hand, refers to exhibition of self-sacrificial, over-protective or over-identification acts by caregivers. Often, over-involvement arises from the guilt experienced by caregivers and the uncertain prognosis of NDD conditions. The expressed emotions construct can be revealed through everyday conversation with others unconsciously

and is thought to be particularly relevant to the caregiving of individuals with chronic disorders marked by cognitive impairment, behavioural disturbance, and/or impairment in daily living (Tarrier et al., 2002).

Relevant to implicit prejudice, Stepahnikova, Triplett and Simpson (2011) have argued that individuals who formerly endorsed negative perceptions about NDD population and have subsequently become a caregiver for child with NDD could still exhibit critical comments through negative affect towards child with NDD. Often, the display of negative affect towards child with NDD appears in subtle manner unconscious to parents.

One prominent illustration of this point is that although mothers of children with NDD report more positive attitudes towards NDD after they take on a main caregiving role for their children, they also report high subjective burden (i.e., feelings of guilt and shame) despite this change in attitudes (Green, 2003). Green (2003) has suggested that these mothers who previously held stigmatizing beliefs about individuals with disabilities may be very aware of the negative attitudes of others. Green's (2003) results indicate that caregivers might hold implicit prejudicial attitudes, even without the caregivers being aware of these attitudes. Findings from the above suggest how expressed emotion towards individuals with NDD may occur unconsciously among caregivers. Additionally, given that the communication of individuals with NDD might be compromised by the presence of one or more of a number of functional and sensory impairments (Howe, 2006), it is highly possible that caregivers might see less motivation in being mindful and exhibit high expressed emotions towards individual with NDD consciously. Given the far-reaching impact expressed emotions has on both caregiver and individual with NDD, it is imperative to examine possible intrapersonal factors (i.e. implicit prejudice) that influence caregiver-child dyadic interaction.

1.5. Research Focus: Implicit Attitudes in Singapore

The degree of implicit prejudice is often culture-specific and caregiver-oriented. As reported by Wong (2015), children are influenced by the culture in which they grow up, including beliefs and others' perceptions, specifically those of their parents, who sharpen their values and socialised practices. Since each caregiver comes from diverse sociodemographic backgrounds and has varying exposure and prior knowledge about individuals with developmental disabilities, there could be varying degrees of self-awareness amongst caregivers about their belief systems related to NDD.

A review on Asian caregivers of children with intellectual disabilities by Ghosh and Magana (2009) found that the society attribute the causes of disability to maternal's past wrongdoings. Similar cultural attribute ("Hwa-byung") was also found in Korea. "Hwa-byung" is a unique syndrome caused by long-term suppression of intense feeling and endurance of oppressive experiences. A close inspection of "Hwa-byung" (Kim, Hwang & Park, 2017) explained how the promotion of cultural virtues like interpersonal harmony and self-control (Min, 2009) dictated the norms and facilitate development of hwabyung. These examples suggest that cultural elements do play a determining role in caregiver's perception of caregiving.

In Singapore, the Enabling Masterplan Steering Committee (Ministry of Social and Family Development, n.d.) was set-up in 2007 to seek opinions from stakeholders, implement initiatives and various disability awareness public education campaigns to improve awareness about individuals with special needs. An initiative that resulted from it is the annual Purple Parade started in 2013 by Autism Resource Centre, Central Community Development Council, NCSS and partner voluntary welfare organizations (VWOs). The Purple Parade showcases the various talents of individuals with disabilities and has garnered popular support, as evident in increased participation from 4,500 participants in 2013 to 10,000

participants in 2016 (Tan, 2016). Additionally, the online promotional video about the Purple Parade is also immensely popular, with more than 240,000 views and 2,200 shares to date. These seem to indicate an increased awareness among the public, suggesting a possible change in societal attitude towards individuals with disabilities.

Despite these encouraging developments, a recent survey commissioned by the Lien Foundation found that 64 per cent of more than 1,000 people indicated a willingness to share public spaces with the special needs community but was unwilling to interact with individuals with special needs (Lien Foundation, 2016). This suggests that most Singaporeans are merely tolerant, rather than truly accepting of, those with special needs. Additionally, a survey of 1,000 people with disabilities by the National Council of Social Service (NCSS, n.d.) found that 62 per cent feel they are still not accepted. Some examples cited by respondents included the lack of opportunities to contribute or reach their potential by society.

Additionally, research has found that people who regularly encounter individuals with NDD tend to possess negative attitudes about NDDs. For instance, Thaver and Lim (2014) reported a paradoxical situation among trainee teachers in Singapore. Although trainee teachers welcomed the idea of inclusion, they continued to report negative attitudes towards the concept of embracing NDDs in regular classrooms.

The discrepancy between the tolerant attitude that is publicly promoted and the prejudice that is held by individuals towards NDDs may come from ignorance, as well as pre-existing culturally-normative perceptions about and attitude towards individuals with disabilities. Prior to the creation of the enabling masterplan, little has been known and done for children with NDD (Foo, Yap, & Sung, 2015; Walker & Musti-Rao, 2016). Little is known about the long-term feasibility of such initiatives as their success thus far is based on a

small pool of caregivers who were not previously exposed to NDD conditions and had minimal contact with other caregivers in the NDD community.

1.6. Research Overview and Research Question

With the acquisition of a caregiver role for individual with NDD, caregivers are faced with ambiguity in one's status in society. There is a need to understand how caregivers cope with the sudden identity transition and increased caregiver demands influence emotional affect and behaviour towards individual with NDD. Additionally, the similarity in underlying components between implicit prejudice and affiliate stigma suggest possible correlation between two variables. Focused on understanding implicit attitudes towards NDD population in Singapore, the following research questions and hypotheses were proposed.

1. How does the attitude of public towards individuals with NDD compare with perceived public attitude by caregivers?

Hypothesis 1: Consistent with previous findings, it is expected that the public will report positive attitude towards individuals with NDD while caregivers of individuals with NDD will reported negative perceived public attitude.

2. What is the relationship among implicit prejudice, affiliate stigma and expressed emotions?

Hypothesis 2: It is expected there is a positive correlation among implicit prejudice, affiliate stigma and expressed emotions.

3. How does attitudes (implicit prejudice, affiliate stigma) of caregivers about NDD influence the quality of caregiving (perceived social support, caregiver burden and subjective well-being) and expressed emotions towards individuals with NDD?

Hypothesis 3: Caregivers of individuals with NDD who report high level of negative implicit attitude will report low quality of caregiving (lower perceived social support, higher

caregiver burden and lower subjective well-being) and high expressed emotions towards individuals with NDD.

4. Is there a discrepancy between level of key variables reported (i.e. implicit attitudes, affiliate stigma and expressed emotions) in qualitative interviews and quantitative self-report questionnaire with primary caregivers?

Hypothesis 4: Caregivers with are in denial about NDD diagnosis of individuals will have discrepancy in levels of variables reported in qualitative interviews and quantitative self-report questionnaire.

To test the hypothesis and understand influence of pre-existing implicit prejudice on affiliate stigma and expressed emotions, I plan to conduct two studies to examine the four hypotheses, the first study is intended to test hypothesis 1 and 2 while the second study is intended to explore all four hypotheses.

1.6.1 Study 1

To understand the influence of the Singapore cultural context, Study 1 was conducted via self-reported online questionnaires among the public to understand (a) self-reported public perception towards individuals with NDD and (b) the relationship among key variables of interest (implicit attitudes, affiliate stigma and expressed emotions). Through cluster analysis, correlation, regression and exploratory factor analysis respectively, the first study will (1) derive the knowledge and perception of public (i.e. current university students and parents of typical child) about NDD in Singapore, (2) understand the relationship between stigma and attitudes, and (3) refine and reduce the number of scale items on survey so that it scales items are relevant to people living in Singapore. The rationale for objective 3 will be further discussed in Chapter 3.

1.6.2 Study 2

The second study was intended explore all hypothesis using caregivers of individuals with NDD to seek the caregiving experience for NDD population. Study 2 was conducted in order to understand the influence of implicit attitude on caregiver's health and dyadic interaction with children with NDD. Using primary informal caregivers of NDD in Singapore, Study 2 adopted a mixed methods convergent parallel design (Creswell, 2003; Tashakkori & Teddlie, 1998) to develop a psychological and culturally based framework that can be used to predict the (a) direct influence of pre-existing attitudes and affiliate stigma on expressed emotions as well as (b) indirect influence of pre-existing attitudes and affiliate stigma on quality of caregiving (i.e. caregiver burden, subjective well-being, perceived social support).

As attitudes about persons with NDD and the problems facing caregivers of persons with NDD are both sensitive but understudied topics in Singapore that require in-depth exploration, this study adopted a combination of both quantitative and qualitative methods. This multi-method approach allowed a collation of multiple perspectives to account for stigma prevalence in Singapore and enhance the understanding of caregiving phenomena for NDD in Singapore context (Creswell & Clark, 2011; Denscombe, 2003).

Implicit prejudice and affiliate stigma are the two dispositional factors that will be closely examined in this study as there is a lack of literature about these factors and their relationships with expressed emotions. Although no prior pilot study or data is available in Singapore, existing literature data favour the prediction that caregivers with high level of negative attitude towards NDD are more likely to report higher affiliate stigma and expressed emotions (Lancaster, Balling, Hastings, & Lloyd, 2014). Results of this study would serve as a confirmation about the prevalence of implicit prejudice among the older generation (i.e. above 21 years of age) and could reveal the role that implicit prejudice plays in influencing

interaction between caregiver and individual with NDD. If the hypotheses are true, this preliminary finding will lend support to a research agenda framework to (a) better understand the impact of culture, social issues, stigma, and discrimination surrounding the NDD caregiving community and (b) focus on implementing campaigns that target pre-existing attitudes about NDD.

1.7 Scope of Research

The study only considers adults above the age of 18 who are living in Singapore. Specifically, study 2 seeks to recruit informal caregivers of NDD living in Singapore. Previous literature reviews have suggested that most caregivers are mothers (Ali, Hassiotis, Strydom, & King, 2012; Cummins, 2001; Pousada et al., 2013; Werner, Corrigan, Ditchman, & Sokol, 2012). Thus, limited knowledge is known about other caregivers like fathers, grandparents or relatives. Hence, I made the decision to not restrict caregiver gender and role of caregivers to be capture a more representative sample of the caregivers in Singapore.

Additionally, there was no restriction on the age of children with NDD. This was done to enhance the understanding of caregiving for older parents. A recent study (Wright, Brooks, D'Astous, & Grandin, 2013) explicitly stated the need more research to study a wider age range of caregivers since caregiving for children with NDD is a life-long commitment.

1.8 Outline of Chapters

This chapter explains the rationale and describes the focus of this research. It also lists the research questions and corresponding hypotheses to be tested, provides operational definition of key concepts examined in this study, as well as highlights the significance of the entire research agenda. The relevant literatures will be discussed in Chapter Two, and Chapter Three outlines the research design and methodology employed for this research. Findings from the research will be presented in Chapter Four. Chapter Five will discuss the

findings and their implications. Limitations of the research will also be discussed in this concluding chapter.

CHAPTER TWO

LITERATURE REVIEW

This chapter provides an overview and justifies my conceptual framework. The first section of this chapter assesses existing theoretical models used to investigate caregiving dynamics and explains my rationale for adapting the Pearlin stress process model of caregivers (Pearlin et al., 1990) as a framework for investigating my research question. Next, I will use my adapted theoretical model to outline the literature review available thus far about the relationship between implicit prejudice, affiliate stigma and perceived social support as well the relationship between these factors and caregiver's subjective well-being and expressed emotions within the caregiver population.

2.1. Theoretical models of stress and coping of caregivers

In investigating the antecedents and consequences of psychological stress, coping strategies and appraisal of caregivers, notable models include the cognitive transactional model of stress (Lazarus, 1966; Lazarus & Folkman, 1984) and stress-process model of carers (Pearlin et al., 1990).

The Cognitive Transactional Theory of Stress. According to the cognitive transactional theory of stress and coping (Lazarus, 1966), the perception of stressors by an individual is greatly dependent on the availability and utility of external resources (i.e., social support), internal resources (i.e., education) and coping strategies. Stress is only reported when personal resources are perceived to be insufficient in relation to the demand of stressor (Lazarus, 1966). Using caregivers of individuals with cerebral palsy as an example, perceived caregiver stress was found to be mediated by parental self-perception (personal resources) and family functioning that served as a form of coping (Rainer et al., 2005). Within the context of appraisal, Lazarus and Folkman (1984) highlighted three types of stress appraisal, namely harm, threat, and challenge.

Evaluation of Cognitive Transactional Theory of Stress. While I acknowledge the importance of primary and secondary cognitive appraisal in understanding the stress process within caregivers, I feel that the utility of this model is restricted to understanding how caregiver's appraisal influences each isolated stress situation. In terms of understanding how pre-existing appraisals within individuals influence emotional interaction with individuals with NDD, Lazarus' (1966) stress and coping model may not be the best model. Essentially, it must be understood that each caregiver endorses a certain set of schemas and thoughts prior to caregiving. While there is presence on cognitive appraisals within Lazarus' stress and coping model, the cognitive appraisals investigated seem to revolve mainly around the caregiver role of an individual in predictable situations and hinges on the assumption that individuals have the knowledge to appraise the situation. The primary appraisal and secondary appraisal suggested by Lazarus may not follow a linear fashion in reality. In addition, the seeming clear cut manner of categorizing a primary appraisal may not be as applicable when studying caregivers of individuals with NDD, given that the sudden revelation of child's diagnoses at around age three may throw caregiver's off-guard to the point where they are often least concerned with appraising the child's NDD situation in relation to self. The fundamental focus on coping strategies rather than purely also suggest a misalignment in interest for this study.

Pearlin Stress Process Model. The Pearlin stress process model (Pearlin, Menaghan, Morton, & Mullan, 1981) explains why caregiving is stressful, and is often used as a framework in research work investigating demographic, cultural and life-history influences of caregiving. Within the framework, five domains contribute to caregiver burden: demographic/context of caregiving, primary stressors, secondary stressors, appraisal and mediators/moderator (coping and resources). The primary stressors include NDD's disability primary diagnosis, caregiver's and NDD age at point of diagnosis. Secondary stressors here

relate to caregiver role strain and employment status. Appraisal in this model refers to the extent of implicit prejudice and affiliate stigma caregivers internalised. Depending on both caregiver's interpretation of child's NDD situation and availability of resources for caregivers, each caregiver will report varying extent of caregiver burden. Adaptation outcome refers to the behavioural change as a result of primary stressor and caregiver stress outcome. The framework can account for many influential factors, which can include demographic, cultural and life-history influences.

Decision to use the Pearlin Stress Process Model. While the initial conceptualization of model was specific to Alzheimer's caregivers and has been said to be applicable to all caregivers, the similarity in experiences that Alzheimer's caregivers and caregivers of individuals with NDD makes this model extremely adaptable. Firstly, the diagnosis of both conditions take place along the one of the life course stages (most NDD diagnosis around age 3). The sudden presentation of diagnosis means that caregivers need to prioritize one's caregiver role over other roles played in everyday life. For most, the need for a constant caregiver to be on the lookout for the care-recipient meant making the caregiver role a priority (in the past, caregiving used to be just one of the many roles played by individuals). The shift also meant that caregivers need to adjust and at times make sacrifices. All of these could potentially affect the thoughts and behaviors of caregivers towards NDD.

Two main differences between Alzheimer and NDD make research using the stress-process model interesting. Firstly, apart from the multi-factor demands of caregiving, caregivers and NDD population often must deal with the societal stigma prevalent in most societies. As members of a society, caregivers are prone to internalize such stigma schemas. A study done by Chong, Saporito and Na (2015) suggested that the internalization process of affiliate stigma may result in perceived public negativity by parents.

Secondly, there is increased subjective caregiver burden for caregivers of individuals with NDD. As individuals with NDD are just starting out in life, caregivers are probably more stressed with the planning and mapping of child's route. Additionally, the lowered capacity of individuals with NDD to functioning typically within society would suggest that every decision made by caregiver is final.

2.2. The proposed conceptual framework

This research situates informal caregiver's pre-existing attitude as a background factor to explore the indirect and direct effects among affiliate stigma, mediators (caregiver burden and subjective well-being) and expressed emotion towards individuals with NDD in Singapore. Figure 1 presents the conceptual model that will be examined in the present study. The model examines the direct association between cognitive appraisal (implicit prejudice, affiliate stigma) and expressed emotion as well as indirect association between cognitive appraisal and expressed emotion, as mediated by the caregiver stress (caregiver burden, subjective well-being) described above. Furthermore, cognitive appraisal and caregiver stress outcome are hypothesized to be mediated by secondary appraisal while caregiver stress outcome is said to mediate cognitive appraisal and expressed emotion.

Figure 1. Conceptual Framework

In the following sections, I will be using the proposed conceptual model as a framework to discuss the relevant findings based on other researchers' work.

2.3. Background and Context: Understanding Singapore and Pre-Existing Attitude

One prevalent ideology that majority of Singaporeans endorse is that of a meritocratic society. To quote Emeritus Senior Minister Goh Chok Tong, meritocracy is a “value system by which advancement in society is based on an individual’s ability, performance and achievement” (Prakash, 2014). As such, it is likely that individuals with NDD may be perceived as having inferior status due to a reduced ability in them to succeed in a merit-based society like Singapore. For caregivers of individuals with NDD who self-identify with meritocratic ideals, this inferior status of child with NDD can have dual influence on themselves. Caregivers may bear negative attitudes towards individuals with NDD due to a perceived drop in relative societal status. Alternatively, a caregiver may agree with the lower status of child to the extent that the caregiver internalizes the perceptions societal has on his or her child. Often referred to as affiliate stigma (Mak & Cheung, 2008), caregivers perceive popular stigmatizing notions of NDD to become personally relevant to their lives and can result in lower subjective well-being (Link et al., 2001; Ritsher & Phelan, 2004; Rosenfield, 1997).

Apart from the meritocratic ideology, Singapore is a society with a tight-culture where “strong norms and a low tolerance of deviant behaviour” are rampant, as evident in the cultural tightness score of 10.4 out of 12.0 (Gelfand et al., 2011). In an interview session, Harrington, a graduate student involved in tight and loose culture research highlighted how tightness is related to “greater discrimination, more socially stable, orderly and exhibit more personal self-control” (Ours, 2014). This tight-culture, coupled with the presence of rules and regulation in most aspects of Singaporeans’ lives, could possibly explain for the high need for conformity to norms. Specifically, the societal norms include being “normal” (i.e., predictability of situations) and repressing of thoughts for sensitive topic such as race and prejudice.

Pre-existing attitude. According to social identity theory, having acquired the role of a caregiver for individuals with NDD would mean that one belongs to the ‘in-group’ of NDD population. Again, how does that interact with pre-existing implicit attitude to influence caregiver’s feelings and subsequent interaction with child? Social identity theory states that we categorise people into groups, and this process results in the formation of in-groups (us) and out-groups (them) (Tajfel & Turner, 1986). Because we derive our social identity and self-esteem via group membership, there is a tendency for in group favouritism and outgroup derogation.

It is vital that both caregivers of typical children and individuals with NDD are aware of the unconscious transference of implicit attitude to child while they are growing up. While there is little that can be done to reverse the process of implicit prejudice one has, it would be great if people are made aware of the prevalence of prejudice. It is also important to highlight that the societal interactions and norms are some major reasons underlying reason of prejudice.

Across all caregivers of individuals with NDD, implicit prejudice seemed to be working from an unconscious level as most caregivers were candid in expressing how they had yet to attain true acceptance of individual with NDD. Similar to findings from Inclusive Attitude Surveys (Lien Foundation, 2016), caregivers of individuals with NDD in this study reported inability to control behavioural issues of individuals with NDD and negative perceived behaviours like constant staring from public as key reasons for not staying in public places for a prolonged period of time. These rationales suggest unconscious affiliate stigma.

2.4. Primary Stressor: Affiliate Stigma and Caregiver Burden

Affiliate Stigma. Affiliate stigma has been identified as a construct prevalent among caregivers of individuals with NDD, especially among caregivers of individuals diagnosed

with autism spectrum disorder (Gray, 1993; Farrugia, 2009; Mak & Kwok, 2010; Wong et al., 2016).

Across the medical, psychological and sociological literature, studies investigating caregivers of children with NDD have identified the important role public stigma played in influencing the normal functioning of both caregivers and children with NDD. For instance, stigma directed toward children with developmental disabilities has been shown to be associated with parental stress and lack of well-being (Ali et al. 2012).

One possible reason for affiliate stigma could be relational deprivation. As mentioned in Chapter 1, caregivers of individuals with NDD often report being scrutinised by public as a caregiver with poor parenting skills. Coupled with a desire to adhere to societal norms, Mikami, Chong, Saporito and Na (2015) reported that caregiver's perceived public attitude may be reflective of one's level of internalized stigma. Various studies have found that caregivers who report high affiliate stigma tend to experience negative emotions, such as shame, low self-esteem, and anger and conceal their stigmatized status from others (Corrigan and Miller, 2004). In addition, research conducted by Green (2003, 2007) has suggested that affiliate stigma may result in negativity towards their children, resulting in poorer parent-child relationships (Green, 2003, 2007). In view of how caregiver's tendency to report negativity (i.e. negative perceived public attitude) may suggest implicit prejudice, this current study seeks to explore the underlying relationship between affiliate stigma and implicit prejudice.

Thus far, there has been limited studies that examine the concept of affiliate stigma among caregivers of individuals with NDD: one concentrated on family caregivers of individuals with ID or mental illness (Chiu et al. 2013; Mak & Cheung 2008; Mak & Kwok 2010), the second on family members of persons with ASD (Mak & Kwok 2010), and the last on family members of persons with ID (Chiu et al. 2013). These studies relied on quantitative

methodology and used the Affiliate Stigma Scale (Mak & Cheung 2008) to assess affiliate stigma. Overall, affiliate stigma showed positive associations between affiliate stigma and caregiver stress and burden, as well as negative associations to psychological well-being (Mak & Kwok 2010), mental health (Chiu et al. 2013) and positive perceptions in caregiving, such as happiness and fulfilment, strength and family closeness, and personal growth (Mak & Cheung 2008).

Caregiver Burden. Caregiver burden is conceptualized as a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience (Erikson & Upshur, 1989). Within the NDD field, caregivers often report high financial cost of caregiving and unpreparedness for child's NDD condition as factors that increase caregiver burden.

Financial fee for therapy and schools. Previous research conducted in high-income countries reported about the additional financial costs involved in raising a child with ASD (Altieri & von Kluge, 2009). Despite a lack of empirical studies conducted in Singapore, there have been multiple news articles that highlighted how cost is a persistent concern for caregivers. According to Goy (2017), typical average school fees for a full-day childcare amounted to \$1,011 a month, with government-appointed childcare operators to charge between \$720 and \$800 a month respectively for full-day childcare, among other criteria. In contrast, Teng (2018) reported the cost of full-day childcare fees at inclusive preschools to be at least \$1,880 per month.

Subjective caregiving burden. The caregiver's subjective perception of the burden, rather than the perception of other family members or healthcare providers, determines the impact on his or her life (King, King, Rosenbaum, & Goffin, 1999). For most caregivers, the NDD diagnosis of child is something unexpected and can potentially cause major alterations in caregiver's interaction with individual with NDD. There are challenges associated with a

child's diagnosis that can add a significant amount of physical stress and psychological stress for not only the parents, but for the entire family (Spratt, Saylor, & Macias, 2007).

Additionally, most caregivers of NDD are not well-equipped with knowledge about the various NDD condition. Coupled with the behavioural problems and reduced ability of NDD in communication, caregivers of NDD reported lower level subjective well-being during caregiver-NDD dyadic interaction (Ketelaar et al. 2008; Mobarak et al. 2000; Parkes et al. 2009; Raina et al. 2005; Romeo et al. 2010).

2.5. Secondary role strain

In explaining caregiver's affective state towards individual with NDD, one strong proposition about the role of implicit attitude is that the unconscious nature of implicit attitude may conflict with societal expectations about "caregiver" role. According to role theory, each society has a set of traditions and norm about what and how a caregiver "should be" (Romeis, 1986). Given the high tendency of Singaporeans to conform, this conflict may increase the amount of strain (i.e. incongruence between explicit and implicit attitude) caregivers faced. Apart from the societal expectations endowed on caregivers, the number of roles a caregiver play in daily life can also influence caregiver's self-reported burden.

2.6 Secondary intrapsychic strain

The literature reviewed thus far seem to highlight the prevalence of affiliate stigma and implicit prejudice, even though caregivers may be unaware about it themselves. As mentioned in Chapter 1, perhaps the biggest contention for caregivers is how societal expectation of them result in suppression of thoughts about individual with NDD. With time, this suppression will eventually increase to a point where caregivers may just explicitly and consciously portray negative emotions towards individuals with NDD.

To mitigate for any opportunity for that to happen, there is a need to understand caregiver's implicit thoughts about NDD population. In particular, I argue for the need to let

caregivers understand how incongruence between actual and ideal self occurs as a function of caregiver role strain. Factors related to caregiver role strain includes trying to attain/ meet caregiver role expectation, which is dependent on individuals' appraisal.

Social identity theory states that we categorise people into groups, and this process results in the formation of in-groups (us) and out-groups (them) (Tajfel, & Turner, 1986). Because we derive our social identity and self-esteem via group membership, there is a tendency for in group favouritism and outgroup derogation. According to social identity theory, having acquired the role of a caregiver for individuals with NDD would mean that one belongs to the 'in-group' of NDD population

2.7 Outcome: Subjective Well-being and Expressed Emotion

Subjective well-being is defined as a normally positive state of mind that involves the whole life experience and encompasses life satisfaction and happiness (Cummins et al., 2001). As in typical children, children with NDD will transition through different developmental milestones (i.e. puberty). This effectively means that coping skills have to be dynamic adjusted to manage NDD at each specific stages of development.

In any typical situation, caregiving is recognised as a heavy commitment duty as caregivers have to be mindful about their emotional state as there is high tendency for caregivers to exhibit negative affective responses towards person in care (Scharlach, 1987).

Research also indicated that the emotional well-being of parents is affected (King et al. 1999) by the enormous responsibility of providing the level of care required by children with ID. Their needs can far exceed those provided in typical parental care, contributing to parental stress and lowering the parent's emotional well-being (Cramm & Nieboer, 2011).

Parents' emotional well-being, however, is negatively impacted by restriction of their social activities owing to caregiving tasks (King et al., 1999), which in turn affects the quality of life of their children. Parental stress is known to increase criticism, hostility and

emotionally over-involved attitudes towards children with ID. This negative emotional content of interaction between children with ID and their parents is considered an important predictor of poor quality of life and enhanced behavioural problems in the children (Hastings & Lloyd, 2007).

Some important contributors to caregiver psychological well-being include the child's functional level (behavioural problems,) and level of dependence on caregiver, (Baker et al., 2003; Blacher and McIntyre, 2006; Pearlin et al., 1990; Raina et al., 2005). In fact, King and fellow researchers (1999) identified child behavioural problems as an important indicator of caregiver psychological well-being.

2.8 Role of Perceived Social Support

Perceived social support refers to the subjective self-affirmation that one is affiliated with a mutually supportive network which provides love, care and concern for oneself (Kim, Sherman, & Taylor, 2008).

Various studies have found positive associations between affiliate stigma and caregiver burden, as well as negative associations to subjective well-being (Mak & Cheung, 2008; Mak & Kwok, 2010; Werner & Shulman, 2013). While studies have shown that strength of social support as a buffering variable, the prevalence of societal stigma towards NDD and associated stigma often reduces both actual social support and receptivity towards potential social support (Maroney, 2001).

Zeidner and Ben-Zur (2013) noted that perceived social support is often more advantageous as a resource than actual social support rendered. This is supported by Lam, Giles, and Lavander's (2003) study that investigated the level of perceived social support and expressed emotions among caregivers of students with NDD.

In relation to caregiver's health, Canary's (2008) systematic review on social support research reported perception of actual social support and its effectiveness to be associated

with reduced parental stress, greater parental empowerment, and high levels of marital satisfaction. However, findings by Ushida, Kitayama, Mesquita, Reyes, & Morling (2008) revealed that perceived emotional support has little benefits on subjective well-being. The huge variation on influence of perceived social support warrant the need for research to be context-specific.

2.9 Behavioural Outcome: Expressed Emotions

A review of articles on related to the expressed emotions construct among caregivers of children with NDD between 1960s to September 2016 (Romero-Gonzalez, Chandler, & Simonoff, 2018) found only 43 publications, of which only 4 measured level of EE related to caregiver attributions (Wasserman & Mundy, 2010), caregiver burden (Greenberg et al., 2006) and caregiver distress (Bader&Barry, 2014; Hastings, Beck & Hill, 2005).

This suggest a need for more exploration since limited understanding is provided within this field. In particular, there is limited studies on expressed emotions of caregivers in Singapore. This suggest a need to fill in the theoretical gap as construct of expressed emotions across cultures may have close relations with “culturally prescribed values” such as expectation of caregiver role, definition of “behavioural problem” and expectation held towards NDD by caregivers and society.

The need to understand expressed emotion is also supported by research about the relationship issues it may bring forth to parent-child interactions (Costa, Steffgen, & Ferring, 2017). While the relationship between positive and negative cognitive appraisal and family functioning varies across research findings, there was an overall revelation that appraisals affect, and outcome are related. Negative appraisals have been associated with higher levels of psychological distress in the family system, higher parenting stress, and a negative impact on the family (Paynter et al., 2013). However, no one looked into the possible intrapersonal history factors influencing appraisal process.

CHAPTER THREE

STUDY 1

This chapter provides information about the quantitative and qualitative methods conducted as part of this research project. I begin this chapter with an overview and rationale of the general research design. Information about the respective research design, sample, instruments, data collection procedures as well as statistical analyses employed in Study 1 will be discussed in the subsections.

3.1 Initial Theoretical Drive and Plan of Overall Research

The initial plan for Study 1 was to conduct a survey using two separate population of participants. In particular, the first study sought to assess the general attitudes towards individuals with NDD in Singapore by recruiting typical population. The second study sought to understand the relationship among key constructs of interest (attitude towards individuals with disabilities, affiliate stigma and expressed emotions), and provide cultural validation of lengthy standardized scales for key constructs of interest through recruitment of informal caregivers of individuals with NDD.

Based on the exploratory factor analysis of the three lengthy scale items, Study 2's refined questionnaire was intended to assess the relationship between key variables (implicit prejudice, affiliate stigma, expressed emotions), mediators (caregiver burden, subjective well-being, perceived social support and dependent variable (expressed emotions), as reported by a separate sample of caregivers of individuals with NDD.

However, the inability to access to a large sample size of informal caregivers in Singapore for cultural validation of standardized scales and structural equation modelling necessitated modifications to initial method designed to study the phenomenon of prejudice among caregivers of individuals with NDD in Singapore.

Emergent concern about sample for quantitative structural model analysis. To conduct structural equation modelling, Kline (2011) recommended a sample size to-parameters ratio of 10:1. An addition of 10% of participants was adopted to account for attrition rate. (Hair, Black, Babin, Anderson, & Tatham, 2006). Based on the 18 estimated parameters (10 loadings and 8 between construct correlation estimates) in the hypothesized model seen in Figure 2, the sample size required for this study amounted to 198 participants.

In view of the large sample size required, 15 organizations and schools catered towards NDD were contacted since June 2017 to seek their consent in the dissemination of study brochure from Oct 2017-Feb 2018. Despite continuous follow-ups, no organizations affirmed their stance in facilitation of my study. Reasons included organization protocol (i.e., do not facilitate independent graduate research), ongoing studies, timeline issues and reluctance of caregivers of NDD to participate in research. Factoring the inability to access to a large sample size of informal caregivers in Singapore and the constraint in data collection timeline, I altered my research design by incorporating the examination of relationship among key variables and cultural validation of scales into study 1 using the typical population as my sample. Additionally, I added a qualitative component to the existing plan of using quantitative self-report questionnaire in Study 2.

Possible generalizability of Study 1 results to Study 2. Although Study 1 examined relationship between keys variables using a different population from target sample, both samples are obtained from the same cultural setting. Previous literature has found attitudinal constructs (i.e. implicit prejudice, affiliate stigma) towards individuals with disabilities are influenced by societal perceptions (Roehrer, 1969). Additionally, a study conducted by López et al. (2009) highlighted the importance of culture in the expression of caregiver's attitudes and emotional reactions related to individuals with NDD. Lastly, the

chosen scales to measure the three constructs are generalized and applicable to any population within the same cultural setting. Hence, it is believed that the establishment of relationship among key variables in Study 1 can serve to inform Study 2 (i.e. if results of Study 1 can be replicated using the caregiver population in Study 2)

Figure 2. Full Hypothesized Model

3.2 Revised Multimethod Research Design

The current multimethod research conducted two studies, each designed to answer different research questions. Each analysis was a separate study on its own, and the results integrated together in the final discussion section.

Study 1 employed a cross-sectional quantitative design to (a) understand informed laypersons' attitudes and knowledge towards NDD in Singapore, (b) examine relationship between key variables and (c) seek cultural validation for standardized scales (Figure 3). Open-ended questions were embedded within the survey to capture qualitative data for a comprehensive understanding about the effectiveness of measures put forth in Singapore.

Given the sensitivity of the topic, a web-based survey portal (Qualtrics, Provo, UT) was adopted to preserve greater anonymity and likelihood of more honest responses.

Figure 3. Overview of Research Design

3.3. Participants: Informed laypeople living in Singapore.

A convenience sample ($N=290$) of Singapore residents comprising current university students above 18 years of age and parents above the age of 18 with children without disabilities took part in for Study 1. This sample was selected due to the relatively greater access and awareness to knowledge about NDD as compared to general laypeople. Sixty-two participants were dropped from analyses as they failed to complete the study. Subsequent analyses were based on complete responses from 228 participants, of which 70.2 % female participants and 29.8 % male participants. They ranged in age from 19 to 59 years old, with a large proportion (95.7%) aged between age 19-29 and the rest (4.5 %) over the age of 30. The ethnic breakdown was as follows: 210 (92.1%) Chinese, 11 (4.8%) Malays, 5 (2.2%) Indians, and 2 (0.9%) belonged to other races.

In terms of familiarity with NDD, 128 participants (56.1%) reported knowing someone with developmental disability while 100 participants (43.9%) reported otherwise. Among the 128 participants, 111 of them reported the specific NDD diagnosis of acquaintance. The most common diagnosis reported was ASD (44.2%), followed by Down syndrome (18.3%) and intellectual disability (11.5%). Table 1.1 provides a detailed breakdown of the demographic.

Table 1.1
Participant's demographic data

	N	Percentage (%)
<u>Age</u>	228	
19 – 20	105	46.1
21 – 29	113	49.6
30 – 39	4	1.8
40 – 49	2	.9
50 – 59	4	1.8
<u>Marital Status</u>	228	
Single	221	96.9
Married	6	2.6
Divorced	1	.4
<u>Current education status</u>	228	
Parent	5	2.2
Undergraduate	216	94.7
Postgraduates	4	1.8
Both parent and current undergraduate/ postgraduate	3	1.3
<u>Highest education level</u>	72	
O Level	1	.4
A Level	35	15.4
Polytechnic diploma or equivalent	17	7.5
Bachelor	14	6.1
Post-graduate	5	2.2
<u>School's Faculty</u>	180	

Engineering	9	3.9
Science	15	6.6
Humanities, Arts & Social Sciences	129	56.6
Business	17	7.5
Education	3	1.3
Others	7	3.1

3.4. Instruments and Materials

The self-report questionnaire comprised of three sections.

Section A: obtained socio-demographic information of participants. Items included gender, age group, ethnicity, nationality, highest level of education, field of study, housing type (used as a proxy for social-economic status), marital status and employment status.

Information about participant's knowledge and contact with NDD were also sought.

Section B: contained four open-ended response questions. Each question gathered descriptive words and phrases related to individuals with (a) autism spectrum disorders (ASD), (b) cerebral palsy, (c) Down syndrome, and (d) intellectual disability. The four conditions were chosen in accordance with information provided by in a booklet disseminated by National Council of Social Service (2015).

Section C: adapted three standardized measures related to (1) attitude towards individuals with disabilities, (2) affiliate stigma and (3) expressed emotion respectively. All of them have been used in previous studies and have reported adequate psychometric properties. Items on standardized measures were refined based on feedback from pilot study. Descriptions of each scale and corresponding changes are provided below.

Scale of Attitudes toward Disabled Persons. The 24-item Scale of Attitudes toward Disabled Persons (Antonak, 1982; 1985) was adapted to measure participant's attitude towards persons with disabilities in Singapore. To prevent potential response bias, 12 items were worded positively (e.g., "People with disabilities get unfair advantage") while the other 12 items were worded negatively (e.g., "People with disabilities get unfair

advantage”). Participants were required to rate each question on a 6-point Likert scale, ranging from -3 (disagree very much) to +3 (agree very much). Prior to summation of scores, the negatively worded items must be reverse-scored. After summation of scores for 24 items, a constant score of 72 must also be included to ensure that the final score was possible. Final possible scores ranged from 0 to 144, where higher scores indicate more favorable attitude towards persons with disabilities. The original study reported internal consistency coefficients of .88 to .91 (Antonak, & Livneh, 1988). This study reported an internal consistency of .80.

Affiliate Stigma Scale. 21 of the original Affiliate Stigma Scale (Mak & Cheung, 2008) were adapted to measure the internalisation of stigma by primary caregivers providing care to individuals with NDD. To ensure items were adapted to fit the current demographic, the term ‘family member with mental illness/ intellectual disability’ was replaced by ‘child with a developmental disability’.

There are three subcomponents in this reduced scale: (a) 7-item cognitive (e.g., “Having a family member with developmental disability imposes a negative impact on me”), (b) 7-item affective (e.g., “The behavior of my child makes me feel embarrassed”) and (c) 7-item behavioral (e.g., “I avoid communicating with my child in public”) component. Participants were instructed to indicate the extent of disagreement (1) or agreement (4) for each item on a 4-point Likert scale. The higher the score, the greater the amount of affiliate stigma reported by participants. The psychometric properties of the Affiliate Stigma Scale have been supported, including excellent internal consistency between .85–.94 (Mak & Cheung, 2008). In this study, excellent internal consistency was achieved ($\alpha = .95$).

Removal of item from Affiliate Stigma Scale. One item (i.e., “I reduce going out with family member with mental illness/ intellectual disability”) was removed due to

concerns about (a) the ambiguity in wording (“reduce going out”) and (b) repetition of concept in another item (i.e., “cut down contacts with social environment”). The low factor loading of this item (.54) in the original study, as well as the report of excellent internal consistency ($\alpha = .94$) despite omission of three questions in Werner and Shulman’s (2015) research (Mak, & Cheung, 2008), serve to justify the removal of item too.

Family Questionnaire. The 20-item Family Questionnaire (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) is a self-report measure of expressed emotion with two subscales: (a) 10-item “criticism” and (b) 10-item “emotional over involvement” subscales. The criticism subscale examines critical negative attitudes towards NDD (i.e., criticism, negative humour, resentment, dislike, blame) while the emotional over involvement subscale assesses emotional responses that reflect over concern, over identification and overprotectiveness, of which caregivers tend to make decisions on behalf of individuals with NDD. Sample items for criticism and emotional over involvement subscales include “I have to keep asking her/her to do things” and “I often think about what is to become of him/her” respectively. Participants had to rate the frequency of occurrence for each item on a 4-point Likert scale from 1 (never/very rarely) to 4 (very often). The higher the scores for each subscale, the greater level of criticism and/ or emotional over involvement.

Wiedemann et al. (2002) suggested high expressed emotions when one either reports a minimum score of 23 for “criticism” or 27 for “emotional over involvement. The Family Questionnaire has been validated as a reliable alternative (Wiedemann et al., 2002) to the traditional method of Camberwell Family Interview developed by Vaughn & Leff (1976). Good construct validity and subscale internal consistency for emotional over involvement ($\alpha = .78$ to $.80$) and for criticism ($\alpha = .91$ to $.92$) have also been demonstrated (Wiedemann et al., 2002). This study achieved an excellent overall internal consistency ($\alpha = .92$), with

Cronbach's alpha for emotional over involvement and criticism subscales to be .87 and .89 respectively.

3.5 Procedure and Consent

Prior to data collection, the necessary ethics clearance was approved by the Nanyang Technological University (NTU) Institutional Review Board (IRB-2017-03-032-01 in Appendix 3). All measures were administered in English which is the primary language of instruction in Singapore.

Recruitment was conducted primarily through two channels. First, undergraduates were recruited from the School of Social Sciences (SSS) Research Participation (RP) system in exchange for RP credit. To increase variability, university students and parents of typical children were also recruited through posts on online social media portal (i.e., Facebook) and parenting forums. No monetary incentive was provided to participants. To ensure clarity and easy comprehensibility of questionnaires items by Singapore residents, a pilot test was conducted with 12 university students and parents of typical children. Based on the feedback, items on standardized measures were adapted and the answering format was refined for some scales.

A survey link was embedded within the study information for potential participants to have direct access to the questionnaire in Qualtrics software (Qualtrics, Provo, UT). Participants were first presented with an electronic informed consent form. The consent form stated that participation for the study was on a voluntary basis and that they could refuse or discontinue the study at any time without penalty by exiting the survey browser. Participants were also assured that their identity would be kept anonymous when using the data for research. After reading through and acknowledging the electronic informed consent form, participants completed the questionnaire. Specific instructions were added in section C to situate participants in the caregiver role for NDD. This served to increase the

validity of findings related to affiliate stigma and expressed emotions. The entire study took approximately 30 minutes. The survey was created and run between August 2017 and November 2017. (Appendix 4)

3.6 Analyses of Data

The Statistical Package for Social Sciences (SPSS) version 22.0 was used for quantitative analysis. As descriptive statistics was provided in subsection 3.3, this subsection will provide results of the exploratory analysis and cluster analysis. To reduce the number of questionnaire items on the three scales, exploratory factor analysis will also be conducted.

The words collated in open-ended questions will be subjected to content analysis. Word descriptors provided for each condition will be consolidated and categorised into negative, neutral (i.e., factual content included) and positive words. The Affective Norms for English Words (Bradley & Lang, 2010), Merriam-Webster's Collegiate Dictionary (2005), literature review and fact check list disseminated by local government organizations (i.e., National Council of Social Service, n.d.) were used to facilitate the categorizing of affect words. Next, the “word frequency queries” of NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012) was used to identify words and word groups (e.g. stem words or synonym) that occurred most often, as well as the relative and absolute frequency of negative, neutral and positive words.

3.7 Results

Descriptive statistics. Table 1.2 revealed the means and standard deviation of scores for each of the three scales. In particular, descriptive statistics of the SADP scale revealed that the public reported positive attitudes, with most participants scoring an average of 100 out of 131.

Table 1.2

Descriptive Statistics for scores on 3 scales (N=228)

Scores for each variable	No. of sample	Mean	SD	Min	Max
Implicit Prejudice	228	13.2895	9.52412	-11.00	48.00
Affiliate Stigma	228	41.4386	11.18647	22.00	67.00
Total Expressed Emotions	228	48.2018	10.61184	.00	68.00

Correlation between SADP and Affiliate Stigma. The relationship between attitude towards persons with disabilities (as measured by SADP) and affiliate stigma (as measured by Affiliate Stigma Scale) was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was no significant correlation between level of affiliate stigma and attitude towards person with disabilities, as measured by SADP ($r=.09$, $n=228$, $p=.099$).

Correlation between Affiliate Stigma and Expressed Emotion. The relationship between Affiliate stigma (as measured by Affiliate Stigma Scale) and expressed emotions was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a medium, positive correlative between the two variables ($r=.43$,

$n=228, p<.0005$), with high affiliate stigma score associated with higher level of expressed emotions.

Logistic regression to predict factors influencing expressed emotions. The unstandardized and standardised regression coefficients for the variables entered into the model. The variables, affiliate stigma and attitude towards disabled person that were significantly correlated with the criterion variable, expressed emotions, were entered as predictors into a multiple regression using the standard method. A significant model emerged: $F(2,225)=26.636, p<.001$. The model explains 43.7% of the variance in criterion variable (adjusted $R^2=.184$). Table 1.3 gives information about regression coefficients for the predictor variables entered into the model. Affiliate stigma was a significant predictor, with a positive relationship to criterion variable. Attitude towards disabled people, knowledge of disabled and relationship with NDD were not significant predictors of expressed emotions.

Table 1.3

Logistic Regression Predicting Factors of Expressed Emotions

Variable	B	SE B	β	p
AFF STIGMA	.39	.09	.41	<.001
What is your relationship with the person?	.10	.83	.11	.234
Attitude towards persons with disabilities	.07	.11	.07	.482
Do you know of anyone who is diagnosed with developmental disability/ special needs?	.17	2.06	.01	.935

Findings about Factor Structure. The following subsection are the respective results of the factor analysis conducted. All shortened versions of the scales reached at least 47.9% of variance explained in the scale scores and these results were comparable to that of the full versions.

Scale of Attitude towards Disabled Person (SADP). Exploratory factor analysis using Principal Components Analysis on the 24 items of the Scale of Attitude towards Disabled

Person (SADP) were subjected to principal components analysis (PCA) using SPSS Version 22 (Figure 4). Prior to performing PCA, the suitability of data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of many coefficients of ($> .4$) and above. The Kaiser-Meyer-Okin value was .77, exceeding the recommended value of .6 (Kaiser, 1970, 1974) and Bartlett's Test of Sphericity (Barlett, 1954) reached statistical significance, supporting the factorability of the correlation matrix.

Principal components analysis revealed the presence of seven components with eigenvalues exceeding 1, explaining 20.3%, 30.1%, 36.6%, 42.1%, 47.2%, 51.9% AND 56.5% of the variance respectively. An inspection of the scree plot revealed a break after the third component. Using Catell's (1966) scree test, I decided to retain three components for further investigation. This decision was further supported by the results of Parallel Analysis, which showed only three components with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (22 variables x 224 respondents). The two-component solution explained a total of 36.6% of the variance, with Component 1 contributing 20.3%, Component 2 contributing 9.8% and Component 3 contributing 6.5%. After reducing the number of items with factor loading below .4, the three-component solution explained a total of 47.9% of the variance, with Component 1 contributing 23.8%, Component 2 contributing 13.1% and Component 3 contributing 11.0%. The finalized scale had 12 items and report a reliability of .69 for Cronbach's alpha.

Figure 4. Scree plot from Exploratory Factor Analysis of SADP ($N=224$)

Affiliate Stigma Scale

Exploratory factor analysis using Principal Components Analysis on the 21 items of the Affiliate Stigma scale were subjected to principal components analysis (PCA) using SPSS Version 22. Prior to performing PCA, the suitability of data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of many coefficients of ($> .4$) and above. The Kaiser-Meyer-Okin value was .95, exceeding the recommended value of .6 (Kaiser, 1970, 1974) and Bartlett's Test of Sphericity (Barlett, 1954) reached statistical significance, supporting the factorability of the correlation matrix.

Principal components analysis revealed the presence of one component with eigenvalues exceeding 1, explaining 61.4% of the variance respectively. An inspection of the screeplot revealed a clear break after the second component (Figure 5). This was further supported by the results of Catell's (1966) scree test, and Parallel Analysis, which showed

only one component with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (21 variables x 224 respondents). After reducing the number of items with factor loading below .4, the finalized scale 13-item Affiliate Stigma Scale reported excellent Cronbach's alpha reliability score ($\alpha=.95$) comparable to the original 22-item scale

Figure 5. Scree plot from the Exploratory Factor Analysis of Affiliate Stigma Scale ($N=224$)

Family Questionnaire. The 20 items of the Family Questionnaire scale were subjected to principal components analysis (PCA) using SPSS Version 22. Prior to performing PCA, the suitability of data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of many coefficients of .3 and above. The Kaiser-Meyer-Olkin value was .92, exceeding the recommended value of .6 (Kaiser, 1970, 1974) and

Bartlett's Test of Sphericity (Barlett, 1954) reached statistical significance, supporting the factorability of the correlation matrix.

Principal components analysis revealed the presence of one component with eigenvalues exceeding 1, explaining 46.3% of the variance respectively. An inspection of the screeplot revealed a clear break after the second component (Figure 6). This was further supported by the results of Catell's (1966) scree test, and Parallel Analysis, which showed only one component with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (20 variables x 224 respondents). The revised 10-item Family Questionnaire scale also achieved very good internal consistency, with a Cronbach's alpha coefficient of .87.

Figure 6. Scree plot from the Exploratory Factor Analysis of Family Questionnaire ($N=224$)

In summary, the exploratory factor analysis indicated the extraction of two major components for the SADP scale, two major components for Family Questionnaire scale.

3.8 Cluster Analysis Findings

A total of 4470 responses were collated from 228 participants and further regrouped based on similarity in root word and description. The frequency of category for each NDD condition was as followed: (a) ASD ($n=189$), (b) Intellectual disability ($n=195$), (c) Cerebral palsy ($n=103$) and (d) Down syndrome ($n=153$). Out of the 639 categories, a huge majority of the responses turned out to be descriptive about each NDD condition generated mainly from the question itself (i.e. a list of common characteristics was provided within the questionnaire). The remaining ($n=146$) non-factual descriptors were found to be within the Affective Norms for English Words (Bradley & Lang, 2010). A further consolidation of the words from all NDD group into their affect group (i.e. positive, negative or neutral) revealed a slight discrepancy between the number of negative words ($n=75$) and positive affect words ($n=57$).

3.9 Brief discussion

The public generally reported positive attitudes towards individuals with disability. In contrast to the hypothesised model which predicted implicit prejudice (low attitude towards disabled person score) and affiliate stigma to be significant predictors of expressed emotions, only affiliate stigma turned out to be a significant predictor of expressed emotions.

While the results from cluster analysis revealed little discrepancies between positive and negative words, the words generated serve as preliminary understanding of how public describes each NDD condition. As the usage of generalized measures within each of the three scales allowed for scales to be applied to different population within the same cultural setting, results of Study 1 (i.e. establishment of affiliate stigma as a predictor of expressed

emotions among the wider public population in Singapore) can serve as a point of comparison to assess if the result can be replicated using the caregiver population Study 2.

CHAPTER FOUR

STUDY 2

This chapter provides information about Study 2's methodology and results. I begin this chapter with an overview and rationale of the general research design for study 2. Information about the respective research design, sample, instruments, data collection procedures as well as statistical analyses employed will be discussed in the subsections of the methodology. Thereafter, I will provide findings of study 2 and conclude with a brief discussion about these findings.

4.1 **Research Design.**

Study 2 adopted a concurrent triangulation design (Creswell & Clark, 2011) for a comprehensive understanding of the (a) relationship among key variables (i.e. implicit prejudice, affiliate stigma and expressed emotions), and (b) how the caregiver attitude and affiliate stigma influence caregiver's wellbeing and expressed emotion towards NDD in Singapore. In accordance with the design, both semi-structured interviews (qualitative data) and self-report questionnaire (quantitative data) were collected in one session and subjected to individual data analysis. Thereafter, triangulation of data was carried out to assess for convergence validity between themes identified in the semi-structured interviews and the self-report scores on the standardized scales in the questionnaire (Creswell, 2009; McFee, 1992)

Rationale of Research Design. The current research utilizes a multi-method approach because quantitative measurement allows for the examination of strength of associations between the key variables within the framework, while qualitative data from the semi-structured interviews facilitates in-depth understanding about how attitudes influence caregiver role phenomena.

4.2 Participants: Primary informal caregivers of NDD living in Singapore.

A purposive sample of primary informal caregivers of NDD above the age of 21 years-old who understand English and reside in Singapore was recruited. To encapsulate the different transition process and experiences of varied caregivers, no restriction was imposed on age of the child and caregivers were also not restricted to parental relationship. As mentioned in Chapter 3, recruitment efforts for Study 2 started out by seeking respective organizations related to individuals with NDD.

Five participants were dropped from the study, as they became uncontactable after the initial contact. The final sample size ($n=21$) was drawn from Down Syndrome Association ($n=9$), Presbyterian Community Services ($n=1$), SPARKS ($n=3$) and a private Facebook group “Special Children with Autism and Learning Disabilities Support Group (SCALD)” ($n=8$).

Of the 21 primary caregivers who voluntarily participated, 19 were mothers and the remaining two participants identified themselves to be the father and a relative of the NDD patients. NDD conditions reported by the sample included Down syndrome ($n=8$), Autism spectrum disorders ($n=7$), Attention Deficit Hyperactivity Disorder ($n=3$) and intellectual disability ($n=3$).

Participants ranged in age from 21 to above 60, with a majority (33.3%) aged between 41-50, followed by 28.6% between the age of 51-60, 19.0% between the age of 31-40, 14.3% aged 60 and above, and 4.8% aged between 21-30. Majority of the sample were married (90.5%), with only 4.8% of the sample who were divorced and the other 4.8% who were single. Of the 21 participants, 90.5% were Chinese, 4.8% Indian and 4.8% identified themselves to be of another minority ethnicity.

While it is not currently possible to obtain an accurate sample size of the NDD demographics in Singapore (Lien Foundation, 2016), my sample size falls within the

recommended range (Shyu et al.,2010; Strauss, & Corbin,1998) of 10 to 30 participants for qualitative analysis.

4.3 Instruments.

The following subsections describe qualitative and quantitative measures.

Interview Guide Development and Pilot Testing. Based on a review of themes identified from the scoping review, an interview guide with 12 questions was structured into five broad thematic areas (see Appendix 2), namely: 1) about present life daily situation (describing an ordinary day with NDD; what works well/less well in your everyday life?), (2) perceptions on stigma towards NDD as a phenomenon in Singapore, (3) prior thoughts, feelings and exposure to NDD, (4) social support availability and usefulness as well as caregiver role expectation (e.g., What do you think is your role as a caregiver?) and (5) concluding remarks including questions about the future (e.g., What are your expectations and dreams for the future, short and long term?). Additionally, room for both verbal and nonverbal probes (e.g., patiently waiting for interviewee to respond) were created to ensure constructs within the study were well-explored (Rubin & Rubin, 2012). Each interview session was around 90 minutes long.

Pilot Testing. To enhance reliability and trustworthiness of the interview guide (Castillo-Montoya, 2016), seven individuals (faculty member, three special needs professionals and three laypersons) assessed the guide for its structure, length and comprehensibility. The appropriateness (i.e., questions should be non-judgmental and non-leading) and sensitivity of language used in the questions were also examined by three special needs professionals. In addition, I conducted three pilot sessions with laypersons (“practice participants”) who role-played as primary caregivers of NDD and these sessions helped me in logistic preparation, script drafting and familiarization of protocol flow. The decision to pilot-test with laypersons instead of primary caregivers of NDD stemmed from practical

considerations about recruitment (i.e., difficulty in recruitment of caregivers of NDD). Based on the feedback I gathered, questions were then subjected to refinements where appropriate.

Quantitative measures. The self-report questionnaire comprised two sections. The first section obtained socio-demographic information of participants. Items included gender, age group, ethnicity, and nationality, highest level of education, housing type (used as a proxy for social-economic status), marital status and employment status. Information about (1) child's developmental disability diagnosis, (2) relationship between caregiver and NDD, (3) diagnosis of child's condition and (4) other caregiving roles were also sought.

The second section adapted six standardized measures related to (1) attitude towards individuals with disabilities, (2) affiliate stigma, (3) expressed emotion, (4) perceived social support, (5) personal well-being and (6) caregiver burden. Items on measures (1), (2) and (3) were reduced based on results of Study 1. Wordings on scale items were also modified based on feedback provided by three professionals in the field to better fit the cultural context and verbal competence of the sample. Descriptions of the three reduced scales are provided below.

Reliability of reduced Scale of Attitudes toward Disabled Persons, Affiliate Stigma Scale and Family Questionnaire. The revised 12-item Scale of Attitudes toward Disabled Persons had a reliability of .69 for Cronbach's alpha. Similarly, the reduced 13-item Affiliate Stigma Scale reported excellent Cronbach's alpha reliability score ($\alpha = .95$) comparable to the original 22-item scale. The revised 10-item Family Questionnaire scale also achieved very good internal consistency, with a Cronbach's alpha coefficient of .87. All shortened versions of the scales reached at least 47.9% of variance explained in the scale scores and these results were comparable to that of the full versions.

Multidimensional Scale of Perceived Social Support (MSPSS). The 12-item Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988) was

developed to assess perceived social support from a significant person, family and friends. All items are rated on a 6-point Likert scale from 1 (strongly disagree) to 6 (strongly agree), with higher scores indicating greater level of perceived social support. A typical item from the scale is, “There is a special person whom I can share joys and sorrows.” The MSPSS reported high internal reliability (.88) and stability over time (.95), and established construct and convergent validity of the scale (Cecil et al., 1995). In this study, excellent Cronbach alpha coefficient of .90 was reported.

Personal Well-being Index (PWI). The 7-item PWI scale was developed to measure the subjective well-being for each of the seven quality of life domains (PWI; Cummins, et al., 2003, & International Wellbeing Group, 2006). There are seven factors in PWI, including standard of living, health, achieving in life, relationships, safety, community-connectedness, and future security. Each item is rated on a 10-point Likert scale (0= completely dissatisfied; 10= completely satisfied). Scores were summated to obtain an average score. The average score was then converted by shifting the decimal point to the right and referenced to the normal distribution within a population (50-100 points). Studies conducted by Lau and colleagues (Lau, Cummins and McPherson, 2005; Lau et al., 2008) have found that values of normal distribution for Asian populations were generally lower by 10 percentage points. The scale has been validated with adults and achieve good internal consistency, with Cronbach alpha between .70 and .80. In this study, excellent Cronbach alpha coefficient of .96 was reported.

Caregiver Strain Questionnaire–Short Form (CGSQ-SF). The 7-item Caregiver Strain Questionnaire–Short Form was developed to assess the objective and subjective impact of caring for NDD (Brannan, Heflinger & Bickman, 1997). The instrument adopted a 5-point Likert-type scale to measure the degree to which individuals report problematic occurrence (e.g., financial strain) or feeling (e.g., embarrassment) because of NDD’s emotional and

behavioural problems. Scores ranged from 1 as 'not at all' to 5 as 'very much'. Responses were first summed into two subscale scores (objective and subjective strain) and later summated as whole to yield a Global Caregiver Strain score. A summated score of 7.0 is rated as high, with scores between 3.8 and 7.0 rated as medium, and scores lower than 3.8 rated as low. The CGSQ-SF7 displays excellent psychometric properties including an internal consistency coefficient of .89 (Bickman et al., 2010). In this study, excellent Cronbach alpha coefficient of .89 was reported.

4.4 Procedure and Consent

Prior to data collection, the necessary ethics clearance was approved by the Nanyang Technological University (NTU) Institutional Review Board (IRB-2017-03-031-01 in Appendix 5). All measures were administered in English as it is the primary language of instruction in Singapore.

Emails were sent out to 15 different organizations seeking their help in the dissemination of study information (Appendix 6 &7). These organizations included non-profit voluntary welfare organizations (VWOs), government agencies, online support groups and mainstream childcare centres offering the Integrated Child Care Programme. The response rate was 41.7%, with four organizations who agreed to the request: (1) Down Syndrome Association Singapore (DSA), (2) Presbyterian Community Services (PCS), (3) The Society for the Promotion of Attention-Deficit Hyperactivity Disorder Research & Knowledge (Spark), (4) Special Children with Autism and Learning Disabilities Support Group- Singapore (SCALD).

Prior to actual recruitment outreach, I contacted the appointed staff member from each organization and supplemented them with the necessary documents (i.e., indemnity letter as part of organization protocol, brochures, study information and materials). Table 1.4 provides a description of recruitment and scheduling method within each organization.

Despite varied modes of dissemination, all content remained the same. Details of administration included: (a) a study overview provided to participants with the study aims, procedure and ethical guidelines, (b) a sign-up link (Qualtrics, Provo, UT), and (c) provision of \$30 and summarized result findings as a token of appreciation. Through the Qualtrics sign-up link, interested participants could indicate their preferred location (private homes or other community settings) and time for the interview session. A specific day was identified to work out all responses and communicate with participants about initial scheduled sessions in December 2017. Actual data collection took place over a 2-month period from Jan 2018 to Feb 2018. In view of the prolonged gap between scheduling and actual session, reminders were sent out to participants one week before the scheduled data and time.

Table 1.4

Breakdown in organizational types in sample group

Organization	Facilitator	Outreach Mode	Scheduling
DSA	Appointed DSA staff	Appointed DSA staff	Appointed DSA staff
PCS	Integrated Child Care Programme (ICCP) coordinator	Consent form handed out about study	Reply slips relayed back for scheduling via email
Spark	Appointed committee member	Email with URL link for sign-up	Scheduling over emails by researcher
SCALD	Administrator of SCALD	Facebook post with URL link for sign-up	Scheduling over emails by researcher
DAS	Appointed DAS staff	Appointed DAS staff	No signups within recruitment period

Qualitative data collection. At the start of each face-to-face interview, I initiated a brief self-introduction. Next, an informed consent sheet outlining the background and purpose of the study as well as recording of any audio and field notes was provided to participants (Appendix 8). To prevent any socially desirable responses, all participants were assured about the confidentiality and anonymity of repossess. Participation was on a voluntary basis and primary caregivers were informed that they could refuse or discontinue the study at

any time without penalty. The interview proceeded once consent was obtained from participants. All interviews questions were conducted primarily in English (Appendix 10).

Quantitative data collection. Following the interview session, participants were required to complete a pen and paper self-report questionnaire (Appendix 9). The questionnaire included a demographic section measures mentioned in the subsection 4.3. Of the six self-report measures, three measures had item reduction based on results of Study 1.

4.5 Data Analysis

The following subsections will describe how qualitative and quantitative data are analyzed. The last part of this section will describe how both data are integrated for further analysis.

Qualitative analysis. Audio-recorded interview data was transcribed verbatim by me, and then translated when necessary into English for analysis via NVivo software (QSR International Pty Ltd. Version 10, 2012). The transcript was subjected to analysis for psychological variables related to caregiving experience in two ways. Firstly, responses were measured in terms of dichotomous categories (i.e., presence or absence of measure variable).

Secondly, the specific reasons and explanations provided by participants for each of the 12 questions were analysed via framework analysis. The process of analysis was both deductive such that it was informed by the framework of priori themes derived from adapted Pearlin Stress-Process Model conceptual framework, as well as inductive with new emergent themes that surface from participant's input. As mentioned in Chapter 2, the similarity in experiences that Alzheimer's caregivers and caregivers of individuals with NDD makes the adapted Pearlin Stress Process Model extremely adaptable for the situation faced by caregivers of individuals with NDD in Singapore.

Framework analysis. Developed primarily for applied policy research, framework analysis is suitable for use in research that has "specific questions, a constrained time frame,

a pre-designed sample and a priori issues” (Srivastava, & Thomson, 2009). Unlike grounded theory framework, the core concern of framework analysis is to relate and deduce what is happening for specific phenomenon (Ritchie & Spencer, 1994). Throughout the data collection process, I concurrently analysed data and sorted in accordance to key issues and themes. As suggested by Ritchie & Spencer (1994), I followed through the five-step process of familiarization, identification of thematic framework, indexation, charting and the last process mapping and interpretation. Participants were given unique pseudonym names which are used when tagging anonymised interview excerpts. The NVivo software (QSR International Pty Ltd, 2012) assisted in coding, cross-referencing, storing, indexing and charting. The process of exploring factors that influence expressed emotions towards individual with NDD in Singapore involved several steps of coding and data reduction. First, I familiarise myself with the data through transcription of participant’s audio-recording, multiple readings and line-by-line coding of transcripts. During this process, I jotted down key ideas and recurrent themes. After familiarization with the data, I proceeded to identify emerging themes through (a) the usage of field notes and (b) constant comparison and contrast between and across all participants. Axial coding was later conducted to develop and minimise the possible categories of response. All cases were coded independently by me throughout the coding process to ensure consistent in coding. To address issues of rigour and trustworthiness, the coding process was reviewed by lab members (i.e. five graduate students, one postdoctoral staff, one research associate members and my supervisor). Within those sessions, I presented my analysis method and way of conceptualising subthemes and themes. After debates and discussion, the final themes presented were based on team consensus as well as consensus from my supervisor. Text files containing descriptive quotes supplementing themes and subthemes were then charted. Through both inductive and deductive process,

relationships between categories, themes and subthemes were then proposed and mapped with supporting verbatim codes from transcripts.

Quantitative data analysis. The Statistical Package for Social Sciences (SPSS) version 22.0 was used for quantitative analysis. In both studies, descriptive statistics will be calculated to provide information about participant characteristics. Cronbach's alphas were calculated to measure the internal consistency of all standardised items, and means, standard deviations and average scores for each of the six variables were calculated. These scale scores have been included to capture each of the six constructs, of which the three key variables will triangulate the qualitative findings via comparison.

Data integration. After data from each approach had been analysed, I compared what caregivers revealed through the interviews and what they self-reported through the questionnaires to see if there was any discrepancy between these two measurements. This serves as a means of triangulation and an enhancement of the qualitative results (Hanson et al., 2005). For this purpose, a table highlighting caregivers who had discrepancies between qualitative data and quantitative data for the three key variables will be presented at the end of the chapter.

4.6 Trustworthiness of Study

Strategies employed to ensure quality of qualitative data. Credibility was ensured by adopting previously well-established research methods (interviews, thematic data analysis), exposing oneself to the culture of primary caregivers of NDD (consultation with several special needs professionals in Singapore; studying various literature review related to caregiving and NDD population, studying appropriate documents and media coverage specific to caregiving and NDD population in Singapore prior to the data gathering) and ensuring honesty of interviewees (providing the opportunity to refuse to participate in the interviews or be audio-taped for the interview). The usage of Nvivo software (QSR

International Pty Ltd. Version 10, 2012) to facilitate data analysis process also increases reliability of results by providing exact references to where coded quotes can be found. This eases the process for other researchers who wish to have an in-depth look at the analysis stage.

Potential Research Bias. Several attempts were made to help control for researcher bias. First, thoughts, opinions and reactions of each participant were recorded in detail as part of my field notes after the completion of each interview. In addition, my thoughts and opinions about the reactions of each participant were recorded as part of my field notes as an effort to make opinions and biases explicit and explain how these may have influenced the interpretation of the data. Attempts were also made to present the results using verbatim quotes from participants so that readers would have a means of evaluating the accuracy of themes extracted. Lastly, all cases were coded independently by me throughout the coding process to ensure consistent in coding. This process continued until all cases were coded and verified.

Strategies employed to ensure quality of quantitative data. The first strategy was to utilise existing standardised measures that are well-validated. Secondly, the construct validity of the reduced survey instruments (implicit prejudice, affiliate stigma and expressed emotions) was established by means of exploratory factor analysis using a geographical representative sample (i.e. residents of Singapore). Thirdly, participants completed the questionnaire immediately after the interview session. This enabled participants to seek clarifications for questions they do not fully understand. Lastly, the convergence validity of the questionnaire was established via triangulation of results to see if the results of the questionnaire and the results of the individual interviews converge or diverge (Creswell, 2009; McFee, 1992).

Strategies employed to ensure quality of mixed-methods data. Mixed-methods validity was examined by adopting two of the nine legitimization types recommended by Onwuegbuzie and Johnson (2006).

(1) Sample integration legitimization was ensured by using an identical sample ($n = 21$) for both self-report questionnaire and semi-structured interviews. This allowed for the development of “meta-inferences” (Tashakkori, & Teddlie, 2003, p. 687).

(2) Weakness minimization legitimization was ensured by complementing the weakness in the quantitative approach (respondents not fully understanding the questions in the instruments) by the strength of the qualitative approach (interviewers could probe responses to ensure clarity and comprehension of questions asked).

4.7 Quantitative results based on interview and survey

Participant profile. Of the 21 participants, nine reported that they were unemployed, four reported that they hold part-time jobs and eight participants reported that they hold full-time jobs. In terms of education qualifications, most participants attained a bachelor’s degree ($n=10$), followed by GCE “O” levels ($n=6$), diploma and equivalent ($n=4$) and postgraduate qualifications ($n=1$). Apart from providing care for child with NDD, six participants had to provide care for other children ($n=6$) and five participants had to provide care for other children and parent ($n=5$). Characteristics of the 21 caregivers are shown in Table 1.5.

Table 1.5

Characteristics of caregivers

Participant pseudonym	Age range	Gender	Education	Marital Status	Employment	Relationship with individual with NDD	Diagnosis of individual with NDD	Other people to provide caregiving for
1) Kate	51-60	Female	O-Level	Married	FT Employed	Mother	Down syndrome	Other Children & Own Parents
2) Penny	Above 60	Female	O-Level	Single	Retired	Relative	Down syndrome	-
3) May	51-60	Female	Bachelor's Degree	Divorced	PT Employed	Mother	Down syndrome	Other Children
4) Jane	Above 60	Female	O-Level	Married	Retired	Mother	Down syndrome	Other Children
5) Sandra	Above 60	Female	A-Level	Married	FT caregiver	Mother	Down syndrome	-
6) Tom	51-60	Male	O-Level	Married	Retired	Father	Down syndrome	Other Children & Own Parents
7) Ashley	41-50	Female	Bachelor's Degree	Married	FT Employed	Mother	Intellectual disability	Other Children
8) Pamela	51-60	Female	O-Level	Married	Retired	Mother	Down syndrome	Other Children & Own Parents
9) Suzy	41-50	Female	Diploma	Married	FT Employed	Mother	Down syndrome	Other Children & Own Parents
10) Cheryl	31-40	Female	Bachelor's Degree	Married	FT caregiver	Mother	Autism spectrum disorder (ASD)	-
11) Anne	31-40	Female	O-level	Married	FT caregiver	Mother	Autism spectrum disorder (ASD)	-
12) Elise	31-40	Female	Bachelor's Degree	Married	FT Employed	Mother	Autism spectrum disorder (ASD)	-
13) Maple	41-50	Female	Diploma	Married	PT Employed	Mother	Autism spectrum disorder (ASD)	Other Children

14) Sanders	41-50	Female	Bachelor's Degree	Married	Self-employed	Mother	Autism spectrum disorder (ASD)	-
15) Amber	41-50	Female	Bachelor's Degree	Married	FT Employed	Mother	Autism spectrum disorder (ASD)	Other Children & Own Parents
16) Krystal	41-50	Female	Bachelor's Degree	Married	FT Employed	Mother	Autism spectrum disorder (ASD)	-
17) Victoria	41-50	Female	Bachelor's Degree	Married	Self-employed	Mother	Intellectual disability	-
18) Pang	31-40	Female	Bachelor's Degree	Married	PT Employed	Mother	Attention deficit hyperactivity disorder (ADHD)	Other Children
19) Valerie	51-60	Female	Postgraduate Degree	Married	FT caregiver	Mother	Attention deficit hyperactivity disorder (ADHD)	Other Children
20) Candy	51-60	Female	Bachelor's Degree	Married	Self-employed	Mother	Attention deficit hyperactivity disorder (ADHD)	-
21) Jamie	21-30	Female	Diploma	Married	FT caregiver	Mother	Intellectual disability	-

Quantitative results from survey. Descriptive of the six variables in the self-report survey are shown in Table 1.6

Table 1.6

Descriptive statistics of each variable

Scores for each variable	No. of sample	Mean	SD	Min	Max
Implicit Prejudice	21	48.43	8.97	34	63
Affiliate Stigma	21	26.76	5.99	15	44
Subjective Well-being	21	52.10	14.28	13	70
Perceived Social Support	21	68.81	10.39	43	84
Expressed Emotions (EOI)	21	12.95	2.60	6	18
Expressed Emotion (Criticism)	21	12.05	2.854	8	19

Overall, caregivers reported positive attitudes towards individuals with NDD ($M=48.43$, $SD=8.97$). Additionally, the self-report of subjective well-being was high ($M=52.1$, $SD=14.28$), with an average score of 7 out of 10. Similarly, high perceived social support was reported ($M=52.1$, $SD=14.28$). Despite the high positive attitude, high level of affiliate stigma was reported among caregivers ($M=26.76$, $SD=5.99$). There was also high level of criticism ($M=12.05$, $SD=12.00$) and emotional over-involvement ($M=68.81$, $SD=10.39$) reported among caregivers.

Correlation analysis between variables. To understand the relationship between variables, non-parametric correlation analysis was run for all variables. The following revealed significant correlations between variables.

Correlation between affiliate stigma and subjective well-being. The relationship between affiliate stigma (as measured by Affiliate Stigma Scale) and subjective well-being was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a medium, negative relationship between affiliate stigma and subjective well-being, $r=-.48$, $n=21$, $p=.029$.

Correlation between caregiver burden and expressed emotions. The relationship between caregiver burden and expressed emotions was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a strong, positive relationship between level of caregiver burden and expressed emotion $r=.73$, $n=21$, $p<.001$.

4.8 Qualitative Findings

All data were analysed and reviewed to identify different aspects of caregiving in Singapore. Participants of individuals across the 4 NDD conditions expressed their subjective experiences of caregiving for individuals with NDD in Singapore and shared their thoughts about perceived public attitudes towards individuals with NDD. Based on my analysis of categories, five main themes comprising factors influencing caregiving and expressed emotions towards individuals with NDD in Singapore were identified and presented in Figure 7. They include:

1. “Me a child”-the pre-existing knowledge of caregivers,
2. “Me as a caregiver”-the role of a caregiver,
3. “Managing my multiple roles”,
4. “Me and my child” - interaction with individual with NDD, and
5. “Navigating me and my child in Singapore”-notion of inclusive society in Singapore.

These themes are described thoroughly, associated with the illustrative quotations from the participants to depict caregiving experiences for NDD population in Singapore. The quotes are presented in mainly English, with the occasional Chinese dialect as is reflective of the verbal style and content of the participants. Each theme has multiple subthemes, however, to illustrate the key findings, only prominent or interesting subthemes and quotes for the main theme will be presented from the empirical material. Table 1.7 presents the details of each theme and subthemes. The relevant illustrative quotes of participants for each subtheme can be found in the Appendix 2.

To ascertain if qualitative results indeed follow the hypothesised conceptual framework, themes from qualitative findings were further regrouped and appraised using the conceptual framework adapted from Pearlin stress process model (Pearlin et al., 1990). A brief overview about the regrouped themes and subthemes is illustrated in Figure 7.

Table 1.7

Overview of themes and subthemes

Themes	Subthemes	Categories
Theme 1: ‘Me as a child’: the pre-existing knowledge of caregivers	Singapore society in the past	Different label for NDD condition
	Personal knowledge	Limited exposure and interaction Restricted knowledge/ wrong conception about NDD condition
	Attitude towards individuals with NDD	Implicit prejudice Pity Empathetic Apathetic Provision of nurturing environment
Theme 2: “Me as a caregiver” the caregiver role of individual with NDD	Caregiver Role conceptualization	Role as an educator Encourager/ Supporter for child
	Acceptance process	Discovery of NDD condition Emotions: sad and in denial Ambivalence of caregivers about accepting NDD diagnosis of child
	Objective caregiver burden	Financial concerns
	Subjective caregiving burden	Dealing with emotional inconsistencies of NDD Need to be patience in repetitive teaching Society attribute blame to parents for behaviour problems of individuals with NDD Affiliate Stigma
	Coping mechanism	Support from school Friend support

		Physical punishment of child with NDD
		Adjust expectation required from child with NDD
		Self-help (emotional regulation)
		Self-empowerment (read up)
		Religion and hope
Theme 3: “Managing my Multiple roles	Managing caregiver role for more than one child	The role of education and provision of equal time between children
	Managing caregiver role and career	Prioritize needs of caregiving for child with NDD
	Managing caregiver role and spousal relationship status	Support from spouse Spousal conflict
	Impact of role overload	Intrapsychic strain: Incongruence between desires and current state of life
	Managing role overload	Informal family social support
		Downward comparison between individual with NDD and other disability condition Personal time as coping mechanism
Theme 4: Me and my child with NDD: Interaction with individual with NDD in Singapore	Interaction as an Educator	Academic-oriented
	Criticism	Internal attribution of negative behaviour of individual with NDD Pervasiveness of implicit prejudice Upward Social comparison between individual with NDD and sibling
		Upward Social comparison individual with NDD and other typical children
	Emotional over-involvement	Protective of individual with NDD- Excessive worry about survival in Singapore

		Protective of individual with NDD- Excessive Worry about individual with NDD in the future
		Self-sacrifice
		Controlling child’s behaviour
	Outcome of expressed emotions	Dyadic interaction between caregiver and child with NDD.
Theme 5: “Navigating me and my child in Singapore”	Attitude and behaviour towards individuals with NDD in Singapore	Presence of implicit prejudice attitude
		Lack knowledge and empathy
		Discrimination
	Cultural values and norms in Singapore	“Kiasu” mentality
		Pragmatic society that values academic competence
	Helplessness in relation to formal social support	Lack of support/knowledge avenue for caregivers
		Insufficient trained professionals
Long waiting time for resources		

Note: Bold phrases are themes covered within Chapter 4 itself.

Figure 7. Illustration of main themes and sub-themes fit in adapted conceptual framework

Theme 1: ‘Me as a child’-the pre-existing knowledge of caregivers. The first major theme category, titled “Me as a Child”, considers the personal history of caregivers that influencing caregiving dynamics for caregivers. Theme 1 encompasses three subthemes relevant to attitude and knowledge of the individual and society in the past. The first subtheme, *Singapore society in the past*, refers to the level of societal awareness back when caregivers were younger. Growing up as a child, caregivers indicated how they were unaware about different NDD conditions as there were no such “labels” within society. Kate, a caregiver between ages 51 and 60, who provided care for her child with Down syndrome, described how society used to be during her younger days:

There’s a lot of grouping in special needs as well...I mean last time never heard of autism ...global...what’s that

In the absence of “labels”, the public tend to attribute behaviour of individuals with different NDD conditions to their character or personality. Often, the descriptors used tend to be negative in nature.

Like ADHD last time huh also have ADHD down syndrome sure have but last time the ADHD people classify back my time they say “gait”[very active; hokkein] , “ji pa si”, last time teacher can cane teacher use the ruler and cane. I also have childhood friend he is ADHD kid back then really cannot concentrate he will up and down like the ADHD kid he cannot concentrate, and he always got behavioural issue...back then teachers can beat what teacher always complain to the mother say he very “gait”. [Maple, a caregiver between ages 41 and 50 who provided care for her child with ASD]

Mongoloid is just special needs...so I cannot recall...what I remember is they are very noisy and they don't sit down they will just play with each other okay... [May, a caregiver between ages 51 and 60 who provided care for her child with Down syndrome]

Personal knowledge. The second subtheme, Personal knowledge, considers the level of knowledge individuals possess about NDD condition prior to being a caregiver. Caregivers acknowledged that there has been no or limited personal exposure with individuals with NDD. One possible reason could be that parents in the past mostly restrained individuals with NDD at home.

But in the past, the down syndrome hardly appear in public one eh...you ask your mother generation I don't think they appear in public ...I'm 60 something my generation they are hidden at home... [Sandra, a caregiver above 60-year-old who provided care for her child with Down syndrome]

Last time parents keep them at home so terrible and they have feelings you know they also feel very sad but they can't talk only you know. [Penny, a caregiver above 60-year-old who provided care for her relative with Down syndrome]

Even among individuals who interacted with NDD population due to work in NDD-related industry, voluntary work at special needs home and contact with friends, knowledge was only restricted to a certain group of NDD. Caregivers expressed stereotypical views and could not distinguish among the various NDD conditions. To quote Elise, a caregiver between ages 31 and 40 who provided care for her child with ASD:

When I was young, when I didn't have a son with special needs, I keep thinking special need should be those like down syndrome, the face is weird...like recognizable at first sight. Now that I have him, I feel that ooh it is not recognizable at first sight that some are special need...a lot of autistic children or children with some problem, it is impossible to tell just by looking at their face."

Attitude towards individual with NDD. The third subtheme, Attitude towards individual with NDD, involves the varied attitude and feelings (prejudice, pity, empathetic and apathetic) caregivers have towards individuals with NDD. In particular, implicit prejudice was prevalent among caregivers.

Among caregivers, there seemed to be misconception and negative stereotypical mind-set about individuals with NDD. This could stem from the stereotypes of individuals with NDD. Sandra, a caregiver aged above 60, who provided care for her child with Down syndrome, attributed "ugly looks" to individuals with Down syndrome. In her exact words:

I prayed 3 things I said god is possible don't down let it be a girl. If is down (syndrome) let it be a boy don't let it be a girl. You know down girl arh, menses next time very difficult. Boy at least one problem less. And I want him to be nice looking. Don't give me a ugly looking one that I don't want to bring outside (laughter) I know, I said because some down can be very ugly looking. I say I don't want a ugly looking child or problematic.

Even among caregivers who indicated feelings of pity and empathy, these feelings seem to arise from subtle negative stereotypes about NDD condition (i.e. seeing individuals with NDD as inferior).

I feel that they are pitiful....sometimes when I go out, I see their parents carry a lot of stuff need assistance I will go up and help as I feel sorry for them....that is how I feel...[Anne, a caregiver between ages 31 to 40, who provided care for her child with ASD]

Generally, I guess because of my personality and character, I will definitely try to have some empathy have a soft spot lah definitely or these kinds of children. I mean after all, they are a bit how to say, I meant they are not like a normal child, so they probably need more support ya so for me I would lah [Amber, a caregiver between ages 41 to 50, who provided care for her child with ASD]

Theme 2: ‘Me as a caregiver’-The caregiver role of individual with NDD. Theme 1 provided an overview about the background and social context of caregivers to enhance our understanding about caregivers’ personal history. The second theme relates how caregivers perceive their role as a caregiver, understand caregiver’s process of realization about individuals’ NDD condition and corresponding acceptance process, and explores the possible relation it has on both subjective and objective burdens of caregiving for individuals with NDD. In trying to navigate the role of being a caregiver for NDD population, it is evident that the personal history of caregivers subtly played a role in the notion and experience of caregiving of individuals with NDD. The four recurring subthemes elaborated in the following paragraphs include (a) the role conceptualization of caregiver duties, (b) the ambivalence of accepting NDD condition of individuals, (c) objective burden and (d) subjective burden.

Caregiver role conceptualization. In describing their perceived duty as a caregiver, caregivers saw themselves playing three pivotal roles- a nurturing caregiver, an educator and a counsellor. In particular, the role of an educator is heavily emphasised as caregivers felt individuals with NDD required more help in managing academic work and in acquiring life

skills. Pamela, a caregiver between ages 51 to 60, who provided care for her child with Down syndrome, described:

I'm with her all the time so I became her teacher and teaching her whatever I want her to know and erm also like for me is that, I was telling myself if I want the output from her I have to give her the input so that erm she is able....and then see how much can absorb and how much can get back to me.

Acceptance process. Although caregivers were primarily the ones who detected NDD condition of child and brought child to the doctor for a formal diagnosis, the process and issue of acceptance prevailed among three groups of caregivers. The first group of caregivers were those that acknowledged the denial child's NDD diagnosis. The second group of caregivers were those who explicitly expressed acceptance of child's NDD diagnosis but implicitly refute the diagnosis, evident from the constant denial-process indicated. In the words of Amber, a caregiver between ages 41 and 50, who provided care for her child with ASD:

I'm very hopeful lah and of course, I'm not sure if you are Christian but for us, for Christian, I'm still claiming complete healing for my boy so I guess there is still this hope.

One similarity between caregivers of the above two group is the continual desire and hope that early interventions would eventually "normalize" individuals with NDD. Sanders, a caregiver between ages 41 and 50, who provided care for her child with ASD, described:

You have to get into emotional situation or so when you are presented with a set of realities but so long as you could entertain the hope, you can entertain the hope, then you entertain it", one reason for the constant denial-acceptance process is due to the continual desire and hope that early interventions would eventually "normalize" individuals with NDD.

The last group of caregivers were those who completely accepted child's NDD diagnosis. When asked about factors that facilitated true acceptance of individuals with NDD, caregivers highlighted the importance of religion, self-education about NDD conditions from online media platforms, books, workshops and interaction with therapist. Elise, a caregiver between ages 41 and 50, who provided care for her child with ASD, summed up her experience:

So I mean to me...generally for parents I feel they can try to educate themselves more....so I think with more education and with more effort on your part to make sure that you have done whatever that you can would actually help you with moving into the acceptance stage lah...

Objective caregiver burden. In addition to perceived burden due to the nature of caregiver role, one prominent objective challenge was the high financial cost of providing care for individuals with NDD across different transition stages of life. Majority of the caregivers ($n=13$) reported expressed a strain in caregiving due the high cost of intervention measures and hospital check-up appointment. Krystal, a caregiver between ages 41 and 50, who provided care for her child with ASD, described:

Stress about ya lah...financially...I think special kids also a lot of extra spending you know...one is special intervention...and also he is enrolled in private speech therapy class on Saturday ya...ya like 1 hour thing lorh so ya lorh is extra cost

Subjective caregiver burden. In terms of subjective caregiver strain, participants emotional stress from (a) dealing with emotional inconsistencies of individual with NDD, (b) patience in repetitive teaching, (c) stress caused by their public attribution of blame for their child's diagnosis and (d) affiliate stigma. Two outstanding subjective burden were the public attribution of blame on caregiver's for behaviour exhibited by individual with NDD and the expression of affiliate stigma by caregivers. In the face of negative societal perception,

caregivers reported defensive and helpless feelings when discussing about the negative perceptions the public have towards individuals with NDD. Elise, a caregiver between ages 31 and 40, who provided care for her child with ASD described:

Some parents do not understand and they think is just ...what do you call that arh... is just this person is just kicking a fuss and maybe people will say the parent did not discipline him or her at home kind and they don't understand that actually is a condition...

In the face of critical public opinion, caregivers who possess implicit prejudice towards individuals with NDD seem to agree with public and expressed elements of negative self-evaluation. Cheryl, a caregiver between ages 31 and 40, who provided care for her child with ASD, aptly described:

You have to keep calm and ignore the people looking at you ...you know and like just tell him red light stop red light stop and ok now green light go now I hardly take bus with him but the train the train is pretty fine he understand that the door open people come in then stop. Personally, I will feel like erm I did not we did not want to cause this noise so it's just temporary it just feel like I don't know. Just feel like I don't want to be a nuisance to the public because you know like yes... that's what I feel because I don't think I should feel embarrassed I mean all of us have our own disability may not be neuro or what but all of us have some issue that we are gripping with

Notably, the comment made by a mother centred upon the justifications she came up for instances where her child screams loudly when taking public transport. Although the mother seemed to be unaffected by the mentioned societal stigmatizing experience, it seemed obvious that she was indeed internalizing the negative attribute of child to her own qualities.

Theme 3: ‘Managing my multiple roles’. Having understood both the perception and experience of caregiving for individuals with NDD, this theme refers to the efforts by caregivers to manage the demands of caregiving for NDD amidst other roles that caregivers have in everyday life. These roles included being a caregiver for other children ($n=6$), being a caregiver for other children as well as a parent ($n=5$), being a working adult ($n=13$) and being a spouse ($n=19$). Close inspection of qualitative data revealed no mention as to how caregivers balance between caregiving for individuals with NDD, other children and parents. Nonetheless, there were indicators of role overload in caregivers’ attempt to juggle among different roles. The discussion of subthemes will first revolve around caregivers’ managing of caregiver role for individuals with NDD and (a) other children, (b) career, (c) spousal commitment. The latter two subthemes consider the (d) intrapersonal impact of role overload and (e) various coping mechanism used to manage role overload.

Managing caregiver role for NDD and other child. Caregivers indicated a strain in sibling relationship. Two methods for coping with the task of managing each child included the usage of education to equip typical child with knowledge about NDD and resistance of delegating secondary caregiving responsibilities for individual with NDD to other children. As mentioned by Pamela, a mother between ages 51 and 60, who provided care for her child with Down syndrome:

The most important thing is when they were young right; you have a special need child but then remember the other child is a typical child but that one is still a child. The minute you burden that child for this child, resentment will grow and then the minute they get older, they will hate that child they will hate the sister.

Ultimately, the core message in maintaining sibling’s relationship is to allow informed independent interaction between siblings without any coercion or stress introduced by caregivers.

Managing caregiver role and career. In total, six caregivers altered their work in order to accommodate to the demands of caregiver role. Specifically, three participants voluntarily chose to quit his/her job and focus on caregiving, two participants made a swap from full-time to part-time work and the last participant was forced to quit her job. Reasons for stronger identification with caregiver role included the need to accompany individual with NDD around, and the desire to spend more quality time with individual with NDD. Amber, a self-employed caregiver between ages 51 and 60, who provided care for her child with ASD, described:

Ya but it's tough for me you know. I have a career and I want to do more, even now.

So but maybe these few year must be very critical for her development that's why I'm now...

Managing caregiver role and spousal relationship status. Eight caregivers discussed the balance in caregiver role and quality of marriage relationship. Apart from one caregiver who indicated presence of date nights with husband, the remaining seven caregivers expressed that their couple relationship revolved mainly around caregiving arrangements made for individuals with NDD. Caregiving arrangements included the appointment of main caregiver, education methods and plans for child. Among these caregivers, five caregivers reported a healthy relationship with spouse while the other four caregivers reported an unhealthy relationship with spouse due to differing acceptance level of individual with NDD and burden on financial cost of caregiving for individuals with NDD.

Ya so actually my husband is very very erm very helpful in a sense when because this early intervention school the parent have to go with them so is actually...but thank god we have it here nearby so is just walking distance. [Krystal, a caregiver between ages 41 and 50, who provided care for individual with ASD]

Then that time our marriage on the rocks my husband and I erm...the relationship not very good because we always quarrel over her because see, I ask him whether we can put her in some development something, to help her enrichment but he doesn't say it would help her she will be like this. [Ashley, a caregiver between ages 41 and 50, who provided care for her child with intellectual disability].

Intrapersonal impact of role overload. Evident from the above subthemes, role overload is an issue that caregivers face. One possible pertinent impact on caregivers is increased intrapsychic strain due to incongruence between expectations and reality. Particularly, these caregivers envisioned their ideal state to be one in which caregivers can juggle between personal desires and caregiver role. However, caregivers reported making sacrifices to cope with and caregiving for individuals with NDD, suggesting a stark contrast between ideal self. Candy, a self-employed caregiver between ages 51 and 60, who provided care for her child with ADHD, described:

It's tough for me you know. I have a career and I want to do more, even now... I want to do the business, conduct my business more aggressively but because my income is not so much now so I need to do a lot of housework as well and also because we wanted to outsource her study as well but most of them cannot take her.

Managing role overload. In an attempt to alleviate the level of strain and lowered subjective well-being faced, caregivers adopted a myriad of conscious coping strategies (i.e. informal social support and respite time) and unconscious coping strategy (downward comparison with individuals).

Unconscious downward comparison as coping mechanism. Downward comparison refers to the comparison of child with NDD to individuals with other disability condition who are presumably worse off than child. In engaging downward comparison, caregivers implicitly seek for comfort and reassurance that they are not the worst and that their child is

“not that bad”. Maple, a caregiver between ages 41 and 50, who provided care for her child with ASD, described:

Ya even sometimes you must think lah...I'm quite fortunate that my son[diagnosed with ASD] is not serious because like watch a movie only eh their kids also cannot eh I have parents share with me arh they kena kick out by the movie theatre

Personal time as coping mechanism. Among 10 caregivers who emphasised the importance of personal time, only four caregivers indicated actual presence of personal time in everyday life. Sanders, between ages 41 and 50, who provided care for her child with ASD, crucially pointed out the underlying rationale for personal time:

[You] can still very caught of the stress of oh my god what's happening but is no fun when you approach it [caregiving] like is job, it is not a fun thing to do so your child need to see as being playful, like you love being with them...this is a happy life other side how else are they going to live their life. They need to find joy too you know and actually some can find joy but they are weigh down by you because they have to take on your crap is really that...they can't they managing too much to take your crap.

[You need to] find some kind of a balance of your own life and life with the child but is more important erm for the child to see a happy parent then for a child to spend lots of time with the parent so is the, really the quality time but you think about it, that's for any relationship right.

Theme 4: “Me and my child with NDD”: Interaction with individual with NDD in Singapore. Through Themes 1 to 3, one can understand how personal history, caregiver role conceptualization, caregiver role demands and the need to still juggle between other roles in life come together to influence the subjective well-being and stress level of caregivers. The fourth theme involves intra-caregiver factors and considers the influence of cultural values and norms on interaction between caregiver and individuals with NDD in Singapore. It includes four subthemes, mainly (a) Interaction as an Educator, (b) Criticism, (c) Emotional over-involvement and (d) Outcome of Expressed Emotions.

Interaction as an Educator. The first subtheme entails caregiver’s strong desire for individual with NDD to be academic-oriented. In relating their daily interaction with individuals with NDD, caregivers seemed expressed strong desire for child to be able to attend mainstream school or academic-oriented.

They would classify it as mild but I take it as mild actually can be improved or even cured...so ya...so now my only wish is hopefully he can go to mainstream primary school...so now we are trying very hard to let him practice a lot of drawing and a lot of use the finger movement so that he will learn how to write. [Krystal, a mother between ages 41 and 50, who provided care for individual with ASD]

I was still like coaching her her work you know and I was telling myself...sometimes I feel it lah , I said that, is not that mummy want to push in anything, you want to stay in such a school, I have to help you achieve it right...I cannot just let you go that kind of thing. [Pamela, a mother between ages 51 and 60, who provided care for individual with Down syndrome]

Criticism. The second subtheme refers to the critical or negative comments caregivers made towards individual with NDD. Three reasons explained for the presence of critical comments: the internal attribution to child, the pervasiveness of implicit prejudice and upward comparison of individuals with NDD against various groups of individuals (i.e. siblings and typical individuals).

Internal attribution to child. Caregivers attributed unsatisfactory behaviour of child with NDD to intrinsic nature of child. This belief resulted in caregivers to be generally negative about child with NDD. Pang, a caregiver between ages 31 and 40, who provided care for her child with ASD, described:

Every time we have the you know meet the parent session right then the teacher say ooh you know he is well behaved...I couldn't believe it you know are you sure...because at home you know he is like you know moving around and he has problem sitting down...

Pervasiveness of implicit prejudice. Even when caregivers are equipped with knowledge about individuals with NDD, subtle negative stereotypes about individuals with NDD within caregivers still prevailed. This imply that prejudice is resistant to change and can occur subconsciously. Valerie, a caregiver between ages 51 and 60, who provided care for her child with ADHD, commented:

ADHD kids are very impulsive and short-tempered and that they are ...they tell a lot of a bad things even towards teachers, supervisors or even for parents. They are very slow to do something because their attention cannot stay

Upward social comparison. Upward social comparison refers to the comparison of child with NDD against typical individuals in the society, including siblings of child with NDD. One prominent reason for critical comments towards child with NDD stemmed from the inability of child in NDD to uplift the expectations caregivers have of them. Implicitly,

this suggest that caregivers internalized norms and have desires of “normalizing” the child with NDD. Cheryl, a caregiver between ages 31 and 40 years old, who provided care for her younger child with ASD, discussed:

The elder boy is so different he is very talkative sometimes he will bring book and sit close to me .With the younger child, things take on a different dynamic... like things you used to take for granted like eating out and uhm doing simple things become much more ..You need more time or you just don't do it anymore...ya

Emotional over-involvement. Emotional over-involvement refers to the overprotectiveness of child. Being fully aware of the norms and limitations of child with NDD, caregivers who showed signs of affiliate stigma or have subtle prejudice attitude tend to (a) worry excessively, (b) engage in self-sacrificial acts, and (c) control behaviour of child. Tom, a caregiver between ages 51 and 60, who provided care for his child with Down syndrome, commented about the challenges of caregiving for individual with NDD:

The worry has really grown a lot because a special erm child, erm I am worried how how could she cope with independent travelling. Will she get missing? Will she lost her way? Or would she talk to stranger and stranger take her away? These are the changes I have to adapt lah

Outcome of Expressed Emotions. Expressed emotions refers to presence of either (a) criticism, (b) overprotectiveness or (c) a combination of both when asked to describe child with NDD. Although caregivers seemed oblivious that they enact expressed emotions towards child with NDD, they do acknowledge the importance of emotional dyadic interaction between caregiver and child with NDD. Regardless of whether child with NDD is responsive, caregivers expressed the need for parents of individuals with NDD to engage in positive dyadic interaction. Sanders, a caregiver between ages 41 and 50, who provided care for her

child with NDD, provided a detailed explanation about the reciprocity of child with NDD to caregiver's emotions:

So regardless of whether the society wants to stigmatize them or not , sometimes this is also the issue so there is interaction between parent and kids right, but of course with the dynamic flow right although, the stressor the perception is all lead on each other. So the kids are also feeling how far the people are afraid of them then they act out some more but they themselves can also be afraid because some sensory stimulus that maybe has nothing with the public is feeling but they are acting out in this way then the public or parent are horrified of them then it get worse then there are some many factors that is going on even within the autistic person that is independent of the parent and the public. So this is what makes it so complex.

Theme 5: “Navigating me and my child in Singapore”. This theme mainly revolves around caregivers' perception about (a) public attitude and behaviour towards individuals with NDD, (b) thoughts about cultural values and norms in Singapore and (c) caregiver's perception about the formal social support.

Attitude and behaviour towards individuals with NDD. With the recent medical advances in prognosis and government initiatives to promote an inclusive society, caregivers indicated an increase in knowledge and awareness of public towards individuals with NDD. Maple, a caregiver between ages 41 and 50, who provided care for her child with ASD, described:

And also I think for special need kid they have to blend into the social but again social must accept so work both ways lah but the society now is much more better....now I think still got staring I mean normal there are still very bad people there are still very kind of person who give very bad remark....some of them I cannot believe because I read on Facebook I cannot believe people say this kind of thing this

kind of people should be beaten...I don't why some of them tell the parent your child like that you shouldn't bring him out...

Nonetheless, majority of the caregivers still highlighted the presence of prejudice attitude and discriminatory behaviour towards individuals with NDD out to public. Tom, a caregiver between ages 51 and 60, who provided care for his child with Down syndrome, recalled a particular incident:

When she started nursery, I actually put her in mainstream kindergarten and at the same time she was in the EPIC school but I was very, I mean in a way very frustrated with the mainstream kindergarten. Because I was told by the principal to let her go erm one or 2 days later erm after the first day of admission of school. Because they were afraid that parents of normal kids see her then they will say why is there a special needs kids in the kindergarten.

Cultural values and norms in Singapore. One plausible reason for pervasiveness of prejudice attitude among the public and caregivers is the internalization and conformity to social norms of Singapore. These social norms encompassed values like “kiasu-ism” and pragmatism. Particularly, being pragmatic in Singapore meant the need to excel in academics. This could possibly justify for the stronger identification the educator role among caregivers (as observed in Theme 2 and Theme 4). Candy, a caregiver between ages 51 and 60, who provided care for her child with ADHD, described:

In Singapore, many kids is supposed to do just study study study all the time right? And then some things like keeping the room and cleaning the rooms, laundry their clothing, thing the very kind of lower level of the work so I met a lady, old lady on the street at that time I was scolding her, my daughter and then she said. Because she lied about study homework, she said that she didn't need to do a homework and then it was a lie. And then I scold about this on the street because like I don't bad to scold my

daughter in public is not a shame. And then an old lady came to us and then she was listening to our story and she say ooh if you don't study you will become a cleaner or something. That kind of thinking ways are all very common here right. And even in hawker centers, to say thank you to cleaner, to keep trays by ourselves, very natural for me but not Singaporeans. So I think in a kind of society must be changed...

Helplessness in relation to formal social support. Formal social support refers to support obtained from school, government and hospital. Caregivers were happy to see increased efforts in provision of formal support. However, the lack of trained professionals within the special needs field is a pertinent issue that caregivers expressed helplessness about. In the face of limited resources within public sector, most caregivers had to bear with the prolonged waiting time for medical appointments and long waiting list for school enrolment. Ashley, a caregiver between ages 41 and 50, who provided care for her child with intellectual disability, described:

Uhm. I feel that the school probably only have 1 social worker, if I'm not wrong is social worker and 1 psychologist and 1 occupation therapist only. One one one. So to cater for the whole school, I think they only focus on those that really need

Sanders, a caregiver between ages 41 and 50, who provided care for individual with ASD, described how formal support could influence dyadic interaction between caregiver and child with NDD:

I mean this sort of things[lack of resources and social support] doesn't make parents feel like they can really do something about their life. Is not an empowering thing for them. It can make them feel very protected about their children but sometimes because it make them feel helpless. sometimes it make them feel frustrated but there that all those feeling that I described are not great feelings and when the autistic child feel all of those feeling which is basically the anguish of the parent. The parents are feeling it,

to love and protect them or the parents are angry at them ...they are all bad feeling for an autistic person to deal because they are very intense feeling so...

4.9 Comparison of themes

After thematic analysis of transcript, each of the three key variables (implicit prejudice, affiliate stigma and expressed emotions) were coded into dichotomous categories (i.e. yes/no to indicate presence or absence of variable) to facilitate one to one direct comparison with results obtained from quantitative self-report survey. As mentioned in Theme 4, 13 out of 21 caregivers reported discrepancy between qualitative interview and quantitative self-report questionnaire. Table 1.8 provides a quick overview about the discrepancy within each caregiver.

In general, most caregivers were found to expressed presence of variable in qualitative interview but absence of a.) low scores on implicit prejudice or b.) high scores on affiliate stigma and expressed emotions in the quantitative survey. As evident from findings from all five themes and literature review in Chapter 2, the discrepancy in quantitative and qualitative results could be due to unconscious process of cognitive processes (implicit prejudice and affiliate stigma).

4.10 General Discussion

Quantitative findings. Findings from correlation analysis revealed a negative association between affiliate stigma and subjective well-being. The higher the level of affiliate stigma reported by caregivers of individuals with NDD, the lower the subjective well-being. Additionally, there is a strong positive association between expressed emotions and caregiver burden. The higher the caregiver burden, the higher the level of expressed emotions reported. These results further supported existing literature review about the relationship between mediators within the conceptual model (Mak & Cheung, 2008; Mak & Kwok, 2010; Werner & Shulman, 2013; Friedrich & Friedrich, 1981). Particularly, existing

literature have found that positive affect in the mother–child relationship has been implicated in maintaining maternal well-being, both with respect to psychological and physical wellbeing (e.g., Greenberg et al., 2004) and in terms of well-being related to the caregiver role (e.g., Pruchno, 2003).

While results from Study 1 indicated a significant positive relationship between affiliate stigma and expressed emotions, results from non-parametric correlation revealed non-significant relationship between affiliate stigma and expressed emotions. One plausible reason why quantitative result did not reveal significant relations between key predictors of expressed emotion could be due to the small sample size ($N=21$) present within this study that underpowered the study. Additionally, it is highly possible that caregivers are unaware about their own implicit prejudice (Greenwald & Banaji, 2005), thereby influencing the results of scores on SADP scale. Nonetheless, results of qualitative findings supplement possible speculations about positive relationship among prejudice, affiliate and expressed emotions. Existing literature have also highlighted the influence of affiliate stigma on expressed emotions. In particular, parents who had high levels of affiliate stigma had higher likelihood of self-blame and feel responsible for their child’s disability (Ali, Hassiotis, Strydom, & King, 2012). Future studies should seek to recruit larger sample size to accurately assess relationship among key variables quantitatively.

Qualitative findings. Despite the individuality and uniqueness of each child and family, there are some common concerns that across caregivers include making future plans for individuals with NDD (i.e. who to provide care for individual with NDD and employability of individual with NDD), prevalence of subtle discriminatory behaviour among the public and a lack of trained, caring professionals within schools, hospitals and early intervention centre. Among the 21 caregivers, 13 caregivers were noted to have discrepancy between quantitative measurements and qualitative findings for key variables (i.e. implicit

prejudice, affiliate stigma and expressed emotions).Primarily, these discrepancies suggest an underlying implicit denial of child’s NDD condition. Discussions about these findings will be revealed in Chapter 5.

Table 1.8

Participants with discrepancy in interview content and self-report questionnaire

Caregiver	Implicit prejudice		Affiliate Stigma		Expressed Emotions (Criticism)		Expressed Emotions (EOI)	
	QUAL	QUAN	QUAL	QUAN	QUAL	QUAN	QUAL	QUAN
Jamie	Yes	No						
Jane	Yes	No						
Krystal	Yes	No						
May	Yes	No						
Sandra	Yes	No						
Amber			Yes	No				
Penny							Yes	No
Victoria			Yes	No			Yes	No
Pamela	Yes	No					Yes	No
Sanders	Yes	No			Yes	No	Yes	No
Candy	Yes	No	Yes	No			Yes	No
Pang	Yes	No	Yes	No			Yes	No
Tom	Yes	No	Yes	No			Yes	No

CHAPTER FIVE

GENERAL DISCUSSIONS

The purpose of this chapter is to summarise important findings, distil the implications of implicit prejudice and cultural norms in Singapore on caregivers of individual with NDD. The first part of this chapter will summarise and discuss research findings based on the research questions and hypotheses answered. Thereafter, the contributions made to the literature and practical implications of research findings will be reiterated. The last section will assess the limitations, provide directions for future research and end with concluding remarks.

Throughout this research, the aim was to elucidate the strong influence pre-existing attitudes has on caregiver's self-reported experience of caring for an individual with NDD. To facilitate the understanding of how pre-existing attitudes influences caregiving experience for NDD population in Singapore, four broad research questions were proposed:

RQ1: How does the attitude of public towards individual with NDD compare with perceived public attitude by caregivers in Singapore?

RQ2: What is the relationship among implicit prejudice, affiliate stigma?

RQ3: How does attitudes (implicit prejudice, affiliate stigma) of caregivers about NDD influence the quality of caregiving (perceived social support, caregiver burden and caregiver's well-being) and expressed emotions towards individuals with NDD?

RQ4: Is there a discrepancy between level of key variables reported (i.e. implicit attitudes, affiliate stigma and expressed emotions) in qualitative interviews and quantitative self-report questionnaire with primary caregivers?

To understand the influence of Singapore as a background context, Study 1 was conducted via self-reported online questionnaires among the public to understand self-reported

public perception towards individuals with NDD and examine relationship between key variables. Using a group of caregivers of individuals with NDD, Study 2 was conducted via both semi-structured interview and questionnaires to answer all RQs.

5.1 Findings for RQ1: How does the attitude of public towards individual with NDD compare with perceived public attitude by caregivers in Singapore?

As mentioned in Chapter 1, the Inclusive Attitude Survey in 2016 conducted by Lien Foundation found consensus of public attitude towards individuals with NDD in Singapore to be explicitly positive but implicitly negative. Most respondents (64%) expressed the belief that Singaporeans are willing to share public spaces with special needs children but are not willing to interact with them. In addition, a quantitative survey conducted in Singapore by Lien foundation to understand public perception about children with special needs found that only 50% of parents were comfortable with having their children sit next to another child with special needs (Tai, 2016). Results of my research reported similar findings. Specifically, Study 1 revealed generally positive attitudes towards the disabled population while findings from Study 2 reported generally negative implicit prejudice and discriminatory behaviours towards individuals with NDD in public spaces, as perceived by caregivers of individuals with NDD. Consistent with findings about public attitudes from public perspective and caregiver perspective were respectively supported by existing research, there remains a discrepancy between findings for Study 1 and Study 2. Specifically, while the explicit attitudes of the public to individuals with NDD are positive, the attitudes and sentiments reported by caregivers of individuals with NDD, based on their experiences with the public, are negative. The following provides three justifications for the discrepancy.

Quantitative measures and implicit prejudice. One explanation for the discrepancy in findings between Study 1 and Study 2 could possibly be due to the difference in measurement method for assessing attitudes towards persons with disabilities. Study 1 made use of the SADP standardised scale to assess attitude towards individuals with NDD. As quantitative measures primarily assessed explicit prejudice of participants, this meant that participants have the ability to conceal conscious implicit attitudes and can produce socially desirable answer.

Presence of implicit prejudice among caregivers and public. Apart from the conscious component of prejudice attitude, literature review in Chapter 2 have highlighted the unconscious element of implicit prejudice within individuals. This unconscious characteristic implicit prejudice can account for the results of quantitative measures in Study 1 and probably explain why the public may be unaware about the subtle discriminatory behaviours they committed, as reported by caregivers in Chapter 4. These can account for the discrepancy between positive self-report public attitude and negative public attitude perceived by caregivers in both ways.

Statements on SADP scale. Another explanation for the discrepancy could relate to the wording of items on SADP scale. A close inspection of standardised items found presence of words like “should” and “can” regarding attitudes towards persons with disability. As these words suggest imperatives and desirable outcomes, it is possible that the positive attitudes reported by the public could be an envisioned ideal state of the self instead of current state of the self. In other words, there might be some idealized reporting by the participants due to the wording of the SADP. This similar idea has also been found and put forth in previous survey conducted to investigate public perception towards individuals with disabilities (Lien Foundation, 2016; National Council of Social Services, 2018).

5.2 Findings for RQ 2: What is the relationship among implicit prejudice, affiliate stigma and expressed emotions towards NDD?

Results from Study 1 pointed to how affiliate stigma is a significant predictor of expressed emotions. This supplemented existing literature review which also indicated affiliate stigma to be a factor that influence expressed emotions. However, implicit prejudice did not surface as a significant predictor of expressed emotions in Study 1 and 2. As mentioned in Chapter 4 and section 5.1, plausible reasons as to why implicit prejudice did not turn out to be a statistically significant predictor of expressed emotions include (a) the fact that both public and caregivers may be unaware about this prejudicial attitude within themselves and (b) the presence of small sample size in Study 2. As a result, they are unable to accurately self- assess attitude towards individuals with NDD. This is further supported by how the qualitative aspect of Study 2 revealed implicit prejudice to be a plausible predictor of expressed emotion.

Implicit prejudice and affiliate stigma. Across all caregivers of individuals with NDD, implicit prejudice seemed to be working from an unconscious level as most caregivers were candid in expressing how they had yet to attain true acceptance of individual with NDD. Similar to findings from Inclusive Attitude Surveys (Lien Foundation, 2016), caregivers of individuals with NDD in this study reported inability to control behavioural issues of individuals with NDD and negative perceived behaviours like constant staring from public as key reasons for not staying in public places for a prolonged period of time. These rationales suggest unconscious affiliate stigma.

Implicit prejudice, affiliate stigma and expressed emotions. Caregivers exhibited high level of expressed emotions in the form of criticism due to the high level of implicit prejudice and affiliate stigma internalized by self. High level of overprotectiveness occurred due to the

endorsement of negative stereotypes about individuals with NDD. This supplemented findings which highlighted how individuals with NDD were restricted by overprotective caregivers as well as society's preconceived notions and stereotypes about their abilities (National Council of Social Service, 2018).

5.3 Findings for RQ 3: What is the relationship among implicit prejudice, affiliate stigma, mediators (perceived social support, caregiver burden and caregiver's well-being) and expressed emotions towards NDD, as revealed in qualitative interviews with primary caregivers?

As indicated in Chapter 4, results of quantitative survey revealed how affiliate stigma is a significant predictor of subjective well-being. This supplemented existing literature review about the relationship between affiliate stigma and subjective well-being.(Mak & Kwok 2010).

Findings from qualitative interview revealed a) caregivers with high level of implicit prejudice tend to report high affiliate stigma, high caregiver burden and high expressed emotions, and b) caregivers report a positive relationship between perceived support and subjective well-being.

Contrary to my expectations, findings from both the questionnaire and interview in Study 2 revealed that perceived social support did not share a negative relationship with expressed emotions. One possible reason could be the lack of satisfaction in level of perceived social support. As mentioned in Chapter 4, caregivers reportedly mention how they feel that support could be enhanced by the government in relation to financial assistance. Additionally, there is also a general dissatisfaction towards the absence of sufficient trained professionals within the early intervention field.

5.4 Findings for RQ 4: Is there a discrepancy between level of key variables reported (i.e. implicit prejudice, affiliate stigma, expressed emotions) in qualitative interviews and quantitative self-report questionnaire with primary caregivers?

As reported in Chapter 4, 13 caregivers reported contrasting results for key variables (i.e. implicit prejudice, affiliate stigma and expressed emotions) between quantitative and qualitative measurements. This discrepancy could be attributed to the a) ability of interviews for more self-disclosure opportunity, and b) denial by caregivers about the NDD diagnosis of children.

Ability of interviews for more self-disclosure opportunity. As self-report items consist of standardised statements, caregivers may or not identify with those statements. Additionally, it is easier to conceal or deny the feelings experienced when caregivers agree with standardised statements. In the one-to-one interview sessions, caregivers were asked to explain and discuss their own thoughts about individuals with NDD and participants. Essentially, this meant that caregivers have lesser opportunity to conceal their implicit thoughts as the session proceeds. For example, some people try to “correct” for their implicit prejudice, particularly those people who both have a lot of it and are motivated not to be prejudiced (Olson, 2009).

Denial by caregivers about NDD diagnosis of children. Caregivers are motivated to deny the condition of individual with NDD as they remained inclined towards achieving the “ideal” caregiver state where both caregivers themselves and individuals with NDD belonged to the “normal” population. The denial of caregivers is evident from caregiver’s attempt to feel “quite normal via downward social comparison of individual with NDD and other NDD conditions which were perceived to be more drastic by caregiver. The push by caregivers to ensure individuals with NDD complete formal education within special needs schools and act of signing up for enrichment classes suggest a strong desire to ensure child meets at least the

minimum “normal” requirement for employment opportunities. Implicitly, the denial status of caregivers can be attributed to the strong internalization and self-identification of the meritocracy ideology discussed in Chapter 1. Simply put, caregivers choose to formalize the expectations of society on individuals with NDD despite knowledge that individuals with NDD may not be gainfully employed. Doing so would ensure that caregivers themselves and individuals with NDD remain within part of the “societal norm”.

Kiasu characteristic. According to the Oxford English dictionary, kiasu refers to “(of a person) having a grasping or selfish attitude arising from a fear of missing out on something” (OED Online, n.d.). Findings of the 2015 and 2018 National Values Assessment survey conducted among Singaporeans (Baharudin, 2018) revealed prominent values such as “kiasu”, competitiveness, materialistic, blame, “kiasi” (Hokkien for “afraid to die”) and self-centredness to be persistent in Singapore. This meant that most residents are achievement-oriented and do not like to lose out to others. Inevitably, these result in increased tendency for social comparison of individuals with NDD by caregivers, as depicted in Study 2’s findings. In particular, caregivers who were in denial made downward social comparison to portray that his or her situation is not “as bad”. Such social comparison and “kiasu” mentality showed how caregivers in Singapore have internalised the kiasu mentality and thus used downwards social comparison as a means to justify to themselves that they are “normal”.

5.5 Contributions to literature

Study 1. This study enhances the understanding of public perception with the availability of descriptive words for four NDD conditions in Singapore. Currently, there are relatively few peer-reviewed studies that have been published about general measures of implicit attitude toward persons with disabilities using the Implicit Association Test (Pruett & Chan, 2006; White,

Jackson,& Gordon, 2006), which detects the strength of a person's automatic associations between mental representations of concepts. At the moment, there is only Multiple Disability Implicit Association Test (MDIAT; Thomas et al., 2007; Vaughn, Thomas, & Doyle,2011) that looks into implicit attitudes towards general disability. My research is novel as it is the first study to come up with a list of possible stimuli words specific to the context of developmental disability for possible further creation of an adapted MDIAT for the Singapore population.

Study 2. This study contributes to the literature on caregiving for children with NDD in a number of ways. Through the usage of both explicit measurements and implicit measurements, I hypothesised a discrepancy in the attitudes towards persons with NDD, as shown in qualitative and quantitative findings. My hypotheses was supported, specifically, that a) a discrepancy was observed in qualitative and quantitative results among 15 caregivers, and b) a caregiver's level of implicit prejudice increases feeling of affiliate stigma and expressed emotions towards NDD. The current research provides preliminary support in recognition of the role of caregiver's pre-existing intrinsic attitudes and of culture in affecting prejudice towards NDD.

Understanding how the attitudes and beliefs towards NDD are formed in an informed public is a fundamental step in addressing the issue of negative attitudes occurring daily in the society and assessing the effectiveness of current intervention efforts. The results of this study could demonstrate the existence of this type of negative bias and therefore support the importance of self-awareness about feelings about people with disabilities. By increasing our understanding of the role that implicit bias about NDD conditions might play in the caregiving process, there is the potential for the expansion of training curriculum which could help provide better self-care for caregivers as individuals as well as enhance dyadic interaction between

caregiver and NDD. Importantly, it is hoped that doing so can alleviate the denial of caregivers about child's NDD condition.

Secondly, there is no comprehensive model that integrates all predictors that were tested in the current research. Though previous research has suggested factors such as discrimination, acculturation, and conflicts between family, culture, and the new environment influencing the development of anxiety, existing frameworks tend to focus more on understanding coping mechanisms at a specific phase of caregiving. In building a culturally-grounded framework that emphasises the need for life-course progression outlook, this research can provide a stronger case in understanding how caregivers cope with challenges of caregiving individuals with NDD within a specific environment. The proposed model is novel as: (a) it takes into consideration various factors such as implicit prejudice and behavioural impact of caregiver's subjective wellbeing on child, that are largely ignored in the literature; (b) it is grounded in the local context, thereby investigating unique cultural elements that could possibly influence

5.6 Implications for Practice and Policy

This research seeks to explore the caregiving phenomenon for NDD population in Singapore, bearing in mind that there is still a lack of existing psychological research conducted within NDD field in Singapore. As there is continual trend of late marriages and pregnancy in Singapore(Tan, 2015), it is vital that more research is conducted in Singapore to capture the influence of cultural elements on individual attitudes towards NDD population and its subsequent impact on caregiving for individuals with NDD.

In line with the third Enabling Masterplan (2017-2021), the Singapore government has recently announced the creation of a new caregiver support centre to empower caregivers with knowledge and social support in hope of reducing their burden (Lee, 2017). Thus far,

government organizations have looked at the respite care needs of caregivers of individuals with NDD. Apart from supplementing empirical research statistics to the vitality of a caregiver support centre in Singapore, this study urges for the need to introduce training courses to empower caregivers with knowledge about balancing between multiple societal roles and in managing self-expectations as a caregiver and true acceptance of individuals with NDD. There is also a need for education among caregivers and public alike on the role of stereotypes on affect and behaviour towards individuals with NDD. In particular, caregivers need to understand how their personal history and society come together to influence caregiving demands and burden. Doing so can possibly alleviate the incongruence caregivers face within themselves unconsciously, thereby facilitating true acceptance of individuals with NDD.

This study hopes to normalize examinations of the construct of implicit prejudice within the field of research on persons with disabilities. Currently, societal norms dictate that informal caregivers provide the first line of caregiving support. Additionally, traditional cultural values promotes the need of a nurturing caregiver sets the guiding notion that “caregivers should not have negative prejudice thoughts about person in care”. Consciously or subconsciously, such expectations of a caregiver within the society could result in caregivers to set a minimum benchmark standard that they need to achieve. The high expectations and knowledge about what is deemed “socially acceptable” can serve as unknowingly be stressed over how best to provide caregiving for individuals with NDD. Overtime, caregivers will learn to suppress one’s implicit thoughts if they are in public.

Corrigan, Powell, and Michaels (2014) remind us that “evaluating stigma is not sufficient; absence of stereotypes does not promote social inclusion” (p. 466). In normalizing and bringing implicit prejudice to the public’s awareness, this study seeks to get caregivers, public

and researchers alike to acknowledge the existence of implicit prejudice. Nonetheless, caregivers should be reminded that implicit prejudice is not a concept to ruminate upon since these, implicit attitudes likely developed from a young age. Moreover, they are likely to be difficult to inhibit or assess. While it would be good for individuals to be mindful of the prejudice underlying our judgements about individuals with NDD, I acknowledge that such practice may not be feasible in all real-life scenarios.

Moving forward, government and non-profit organizations can implement campaigns or education program via social media campaign or television drama to showcase spread awareness about the influence of pre-existing attitude and knowledge on eventual behaviour and thoughts about individuals with NDD. While Singapore has launched various campaigns (i.e., “ See the true me” campaign by NCSS”) on social media channels to target the youth population, a stronger mode of medium to relay positive message or foster positive interaction with individuals with NDD would be through traditional media (i.e., television, launch of drama or reality shows showcasing individuals with NDD in a positive light).

Ultimately, it has to be noted that no amount of government initiatives can ever work in advocacy if Singaporeans choose to stay apathetic on issues unrelated to them. This notion in particular as been echoed by caregivers within Study 2 and as well as caregivers from Inclusive Attitude Survey (Lien Foundation, 2016). It is hoped that these findings showcase that more discussion about NDD can create the heightened awareness about the pervasiveness of pre-existing attitude. The greater dialogue about NDD might help to effect change of attitudes for future generations.

Despite the increasing prevalence of inclusive kindergartens aimed at increasing positive interactions between typical individuals and NDD, the mindset and expressed emotions

expressed by caregivers during interaction with child still plays a central role in influencing the thoughts and affect children have towards NDD. It is hope that caregivers can at least improve their explicit attitudes and behaviour towards the NDD population. This notion in particularly as been echoed by caregivers within Study 2 and as well as caregivers from Inclusive Attitude Survey (Lien Foundation, 2016).

5.7 Limitations

This research suffered from several limitations in relation to participant pool and choice of methods.

Demographics of participants. Firstly, the results of the study are only generalizable to the current demographics- proficient in English, have access to social support (i.e., online social support groups, formal organizations). It is likely that the high level of perceived social support reported by participants are not representative as they were recruited from online social support groups and offline organizations.

Secondly, there could be also be sample selection bias. All participants who took part expressed an intrinsic desire for change within the Singapore ecosystem and willingness to provide mutual support for each other. The self-empowering qualities are evident from their voluntarily participation and interest in obtaining a summarised copy of research findings. In reality, this demographic may not be a true representation of the entire population of interest. Caregivers who self-identified to have high level of prejudice towards NDD population and high level of affiliate stigma may have been less willing to participate or complete the study.

Lastly, despite efforts to encapsulate the experiences of different groups of primary caregivers such as fathers and grandparents, the voluntary participation nature of this study resulted in mainly recruitment of mothers only.

Rationale for methods utilised in Study 1. Although an attempt was made to provide cultural validation of scales using the public population in Study 1, it is acknowledged that there remains a huge difference between the provision of imaginary scenarios for public in an attempt to mimic caregivers' thoughts and actual caregiver thoughts. Given the constraint in recruiting the intended sample size of 200 caregivers and the necessity for exploratory factor analysis to be prior to the start of Study 2, such a method was enforced as it was the next best alternative.

Rationale for methods utilised in Study 2. While there was a small sample in Study 2, the nature of my study resides in the sensitive topic of prejudice amidst a society with tight social norms. As an independent graduate researcher, this translated to heightened difficulty in gathering sufficient sample size for quantitative analysis. Additionally, since I am studying the taboo topic of implicit prejudice, it could have created greater resistance amongst participants. This might mean that participants' true attitudes cannot be revealed via quantitative measures. Hence, qualitative assessment was an appropriate methodology as it provided me with the ability for insight understanding of concepts and thoughts that is "probably not accessible using techniques such as questionnaires and observations" (Blaxter et al., 2006, p. 172),

Within this study, implicit prejudice of caregivers was detectable only through in-depth discussions, analysis and a) presence of good rapport between researcher and participant that allowed for participants to disclose their experiences of caregiving in Singapore, b) in-depth analysis of qualitative data based on field notes and transcript, and c) direct comparison of qualitative findings with survey results. No qualitative measure can easily capture a sufficient range of the social nuances, interpretations, and personal meaning embedded in the stigma of NDD conditions.

5.8 Recommendations for Future Research

This study introduced new insight about the role of implicit prejudice on caregiver's level of affiliate stigma and expressed emotions towards children with special needs and introduced the need for stress-process model to adopt a life-course progression ideology. While it is acknowledged that the topic of implicit prejudice is sensitive, especially in a highly collectivist culture like Singapore, I believe that with advancement in social awareness and connectedness through social media, the time is ripe for further preliminary and in-depth studies of attitudes towards the NDD community.

Demographics of participants. Several variables were not examined within the current study but could be of interest in future studies. Firstly, I did not manage to recruit any domestic helpers and grandparents in this study. According to the Report on the State of the Elderly (Ministry of Social and Family Development, 2009), more than one in four households living in Housing Development Board (HDB) flats with children aged 12 and younger relied on grandparents as the main care provider, second only to mothers as the main caregiver. Future research should seek to understand how grandparents' level of implicit prejudice influence their experience of caregiving for individuals with NDD, evident from expressed emotions towards individuals with NDD.

Secondly, there was limited access to caregivers of different NDD groups as recruitment efforts were curtailed by other organizations approached who expressed difficulties in accommodating my research within a short timeframe (i.e., can accommodate my research if study took place at least one and a half years later). It would be interesting for future research to dwell into other NDD conditions and understand if there is any correlation between NDD conditions and focus on academic or work opportunities for individuals with NDD by caregivers.

Lastly, while previous studies have shown how different types of disability and age influence affiliate stigma (Krauss & Sceltzer, 1998; Greenberg et al., 1993), the current study is unable to fully understand the impact due to the focus on neurodevelopmental disability as a generic group. Given that each specific developmental disability presents a specific challenge in itself, future research should focus on detailed understanding of the issues surrounding caregiving for each developmental disability so as to gain depth for tailored interventions.

Rationale for method. As mentioned within the section on study implications, future studies can build upon the consolidated list of descriptive words revealed within Study 1 and devise a list of stimuli words to facilitate creation of adapted MDIAT for assessing implicit attitudes towards individuals with NDD in Singapore. This can also enhance the qualitative findings from caregivers when assessing the discrepancy between quantitative and qualitative measures.

5.9 Conclusion

The birth of a child changes the dynamics for couples or existing parents as they now have acquired an additional life-long role of caregiving for an individual. Often, the ambiguity and responsibility of being a parent is intimidating and stressful for first timers. For others, the subjective and objective cost of caregiving for another child may pose an issue and influence their interaction with child. Nonetheless, this caregiver burden experienced by caregivers usually decreases as the child eventually turns 21 and becomes an autonomous adult.

However, the situation changes when a child is being diagnosed with NDD (usually around age three, when the child begins to have more social interactions with similar aged children). As reported by numerous studies, the sudden change in caregiving demands can result in higher caregiver burden, lower subjective well-being and higher expressed emotions. While

affiliate stigma has been identified as one attitudinal component that can influence expressed emotions of caregivers towards individuals with NDD, little is known about the influence of caregiver's implicit attitude towards individuals with NDD.

Given that caregivers themselves would have pre-existing thoughts about individuals with NDD, how does that influence caregiving and interaction with own child diagnosed with NDD? In the event that caregivers do not have prior knowledge or contact with individuals with NDD before, how does the NDD diagnosis of child in Singapore influence caregiving and interaction with child? What contextual factors influence caregiving for NDD population?

Findings from Study 2 revealed generally negative sibling relationships between typical children and individual with NDD. It would be interesting to study siblings themselves to gain their perspective on their thoughts about individuals with NDD. Thus far, results have been based on self-report from caregivers. Interviewing the siblings themselves may reveal a different story. In fact, a study conducted by Dyke et al. (2015) found that siblings may display feelings of empathy towards individuals with NDD.

With the presence of inclusive preschools in Singapore, it would be interesting for future studies initiated by the government to conduct longitudinal studies to investigate if early exposure and contact with NDD influence typical child's implicit attitude towards individual with NDD.

In conclusion, the findings of this study lend preliminary support to the necessity for developing a research agenda to better understand the impact of culture, social issues, stigma, and discrimination for the purpose of establishing that they exist and acknowledging the need for action. Within the NDD field in Singapore, there remain many areas of discovery for researchers. Researchers and practitioners alike must move beyond identifying socioeconomic barriers and

begin to study the complexities and multiple facets of discrimination experienced by caregivers. This requires the society to move past the underlying assumption that caregivers are intrinsically motivated and inherently and uniformly positive towards their children's developmental disability.

REFERENCES

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th Ed.)*. Washington, DC: Author.
- Antonak, R. F. (1985). Construct validation of the Scale of Attitudes toward Disabled Persons. *Journal of Applied Rehabilitation Counseling, 16*(1), 7-10.
- Antonak, R. F. (1982). Development and psychometric analysis of the Scale of Attitudes toward Disabled Persons. *Journal of Applied Rehabilitation Counseling, 12*, 22-28.
- Antonak, R. F., & Livneh, H. (1988). *The measurement of attitudes toward people with disabilities: Methods, psychometrics and scales*. Springfield, IL, England: Charles C Thomas, Publisher.
- Altieri, M. J., & von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies, 18*, 83–92.
- Are, F., & Shaffer, A. (2016). Family emotion expressiveness mediates the relations between maternal emotion regulation and child emotion regulation. *Child Psychiatry & Human Development, 47*, 708–715.
- Ashiabi, G. S. (2000). Promoting the emotional development of pre- schoolers. *Early Childhood Education Journal, 28*(2), 79–84.
- Bader, S. H., & Barry, T. D. (2014). A longitudinal examination of the relation between parental expressed emotion and externalizing behaviors in children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(11), 2820–2831. <https://doi.org/10.1007/s10803-014-2142-6>.
- Baharudin, H. (2018, July 30). Singaporeans describe humour and fun as important in National Values Assessment survey. *The Straits Times*. Retrieved from

<https://www.straitstimes.com/singapore/singaporeans-describe-humour-and-fun-as-important-in-national-values-assessment-survey>

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217–230

Baldry, A. C., & Farrington, D. P. (2000). Bullies and delinquents: personal characteristics and parental styles. *Journal of Community & Applied Social Psychology*, 10, 17-31.

Banaji, M. R., & Greenwald, A. G. (1995). Implicit gender stereotyping in judgments of fame. *Journal of Personality and Social Psychology*, 68(2), 181-198.

Banaji, M. R., & Hardin, C. D., & Rothman, A. (1993). Implicit stereotyping in person judgment. *Journal of Personality and Social Psychology*, 65, 272-281.

Baumrind, D. (1967). Child care practices anteceding three patterns of preschool behavior. *Genetic Psychology Monographs*, 75, 43–88.

Beelmann, A., & Heinemann, K. S. (2014). Preventing prejudice and improving intergroup attitudes: A meta-analysis of child and adolescent training programs. *Journal of Applied Developmental Psychology*, 35(1), 10–24. <https://doi.org/10.1016/j.appdev.2013.11.002>

Bickman, L, Athay, M.M., Riemer, M., Lambert, E.W., Kelley, S.D., Breda, C., Vides de Andrade, A.R. (2010). *Manual of the Peabody Treatment Progress Battery*. 2nd ed. Retrieved from <http://peabody.vanderbilt.edu/ptpb/>.

Bigler, R. S., & Liben, L. S. (2007). Developmental intergroup theory: Explaining and reducing children's social stereotyping and prejudice. *Current Directions in Psychological Science*, 16,162–166.

- Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation*, 112(5), 330–348.
- Blaxter, L., Hughes, C. & Tight, M. (2006). *How to Research*. (3rd Ed.) New York: McGraw-Hill Education.
- Boyle, C.A, Boulet, S., Schieve, L., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M., Visser, S., & Kogan, M.D.(2011). Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008. *Pediatrics*. 27, 1034-1042.
- Bradley, M.M. & Lang, P.J. (2010). *Affective Norms for English Words (ANEW): Instruction manual and affective ratings. Technical Report C-2*. University of Florida, Gainesville, FL.
- Brannan, A. M., Heflinger, C. A., & Bickman, L. (1997). The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. *Journal of Emotional and Behavioral Disorders*, 5(4), 212-222. doi: 10.1177/106342669700500404
- Castillo-Montoya, M. (2016). Preparing for Interview Research: The Interview Protocol Refinement Framework. *The Qualitative Report*, 21(5), 811-831. Retrieved from <http://nsuworks.nova.edu/tqr/vol21/iss5/2>
- Cecil, H., Stanley, M. A., Carrion, P. G. and Swann, A. (1995), Psychometric properties of the MSPSS and NOS in psychiatric outpatients. *Journal of Clinical Psychology*, 51, 593-602.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.

Chavira, V., Lopez, S., Blacher, J., & Shapiro, J. (2000). Latina mothers' attributions, emotions, and reactions to the problem behaviors of their children with developmental disabilities. *Journal of Child Psychology and Psychiatry*, 41(2), 245–252.

Chiu, M. Y. L., Yang, X., Wong, F. H. T., Li, J. H., & Li, J. (2013). Caregiving of children with intellectual disabilities in China - an examination of affiliate stigma and the cultural thesis. *Journal of Intellectual Disability Research*, 57(12), 1117–1129.

Corrigan, P. W., Powell, K. J., & Michaels, P. J. (2014). Brief battery for measurement of stigmatizing versus affirming attitudes about mental illness. *Psychiatry Research*, 215, 466–470.

Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, 13, 537–548.
doi: 10.1080/09638230400017004

Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology Science Practice*, 7, 48–67

Costa, A. P., Steffgen, G., & Ferring, D. (2017). Contributors to well-being and stress in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 37, 61–72.

Cramm, J. M., Nieboer, A. P., 2011. Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *Journal of Intellectual Disabilities* 15(2), 101–113.

Crosby, F., Bromley, S., & Saxe, L. (1980). Recent unobtrusive studies of Black and White discrimination and prejudice: A literature review. *Psychological Bulletin*, 87(3), 546–563.
<http://dx.doi.org/10.1037/0033-2909.87.3.546>

Creswell, J., & Plano Clark. (2011). *Designing and Conducting Mixed Methods research* (2nd Edition). Sage Publications. London.

Creswell, J.W. (2009), *Research Design. Qualitative, Quantitative, and Mixed Methods Approaches*, Third Edition, Thousand Oaks: Sage Publications Inc.

Creswell J (2003) *Research design. Qualitative, quantitative and mixed methods approaches (2nd edn)*. Thousand Oaks, CA: Sage.

Cummins, R.A., Eckersley, R., Pallant, J., van Vugt, J., & Misajon, A. (2003). *Social Indicators Research*, 64, 159.

Cummins, R. A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: a review. *Journal of Intellectual & Developmental Disability*, 26(1), 83–100. <https://doi.org/10.1080/13668250020032787>

Dasgupta, N. (2013). Implicit Attitudes and Beliefs Adapt to Situations: A Decade of Research on the Malleability of Implicit Prejudice, Stereotypes, and the Self-Concept. *Advances in Experimental Social Psychology*, 47.

Deater-Deckard K. (1998) Parenting stress and child adjustment: some old hypotheses and new questions. *Clinical Psychology: Science and Practice*, 5, 314–32.

Denscombe M (2003) *The Good Research Guide for Small-scale Social Research Projects*, 2nd ed. Philadelphia: Open University Press.

Dovidio, J. F., Hewstone, M., Glick, P., & Esses, V. M. (2010). *Prejudice, Stereotyping and Discrimination: Theoretical and Empirical Overview*. In V. M. Dovidio, J.F., Hewstone, M.,

Dovidio, J. F., Kawakami, K., & Gaertner, S. L. (2002). Implicit and explicit prejudice and interracial interactions. *Journal of Personality and Social Psychology*, 82, 62–68.

Dykens, E. M. (2015). Family adjustment and interventions in neurodevelopmental disorders. *Current Opinion in Psychiatry*, 28(2), 121–126.

Erickson, M., & Upshur, C. C. (1989). Caretaking burden and social support: comparison of mothers of infants with and without disabilities. *American Journal on Mental Retardation*, 94(3), 250-258.

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health and Illness*, 31(7), 1011-1027.

Fazio, R. H., Jackson, J. R., Dunton, B. C., & Williams, C. J. (1995). Variability in automatic activation as an unobtrusive measure of racial attitudes: A bona fide pipeline? *Journal of Personality and Social Psychology*, 69(6), 1013-1027.

Foo, M., Yap, P. M. E. H., & Sung, M. (2015). The experience of Singaporean caregivers with a child diagnosed with autism spectrum disorder and challenging behaviours. *Qualitative Social Work*, 14(5), 634–650.

Gaertner, S. L., & McLaughlin, J. P. (1983). Racial stereotypes: Associations and ascriptions of positive and negative characteristics. *Social Psychology Quarterly*, 46, 23-30

Glick, P., Fiske, S. T., Mladinic, A., Saiz, J. L., Abrams, D., & Masser, B. (2000). Beyond prejudice as simple antipathy: Hostile and benevolent sexism across cultures. *Journal of Personality and Social Psychology*, 79, 763-775

Glick, P., & Esses (Ed.), *The SAGE Handbook of Prejudice, Stereotyping and Discrimination* (pp. 3–28). London: SAGE Publications Ltd.

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27(3), 215-222.

Gray, D. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, 15, 102–120.

Green, S. E. (2007). “We’re tired not sad” Benefits and burdens of mothering a child with disability. *Social, Science and Medicine*, 64(1), 150-163.

Green, S. (2003). They are beautiful and they are ours: Swapping tales of mothering children with disabilities through interactive interviews. *Journal of Loss and Trauma*, 8, 1–13.

Green, S. E. (2003). “What do you mean ‘what’s wrong with her?’”: Stigma and the lives of families of children with disabilities. *Social Science and Medicine*, 57(8), 1361–1374.

Goy, P. (2017, July 11). 'Safe environment' for play at early intervention centre. *The Strait Times*. Retrieved from <https://www.straitstimes.com/singapore/education/safe-environment-for-play-at-early-intervention-centre>

Greenberg, J., Seltzer, M., Hong, J., & Orsmond, G. L. (2006). Bidirectional effects of expressed emotion and behavior problems and symptoms in adolescents and adults with autism. *American Journal on Mental Retardation*, 111, 229–249.

Greenberg, J.S., Seltzer, M.M., & Greenley, J.R. (1993). Aging parents of adults with disabilities: The gratifications and frustrations of later life caregiving. *The Gerontologist*, 33, 542-550.

Greenwald, A. G., & Banaji, M. R. (1995). Implicit social cognition: Attitudes, self-esteem, and stereotypes. *Psychological Review*, 102, 4-27

Greenwald, A. G., McGhee, D. E., & Schwartz, J. L. K. (1998). Measuring individual differences in implicit cognition: The implicit association test. *Journal of Personality and Social Psychology*, 74, 1464-1480.

Ghosh, S., & Magana, S. (2009). A rich mosaic: Emerging research on Asian families of persons with intellectual and developmental disabilities. *International Review of Research in Mental Retardation*, 37, 179–212.

Hair, J.F., Black, W.C., Babin, B.J., Anderson, R.E., & Tatham, R.T. (2006). *Multivariate Data Analysis*. New Jersey: Pearson Prentice Hall.

Hanson, W.E., Creswell, J.W., Plano Clark, V.L., Petska, K.S. & Creswell, J.D. (2005) Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology*, 52(2), 224–235.

Hastings R. P. & Lloyd T. (2007) Expressed emotion in families of children and adults with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 339–45.

Hastings, R. P., Beck, A., & Hill, C.J. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers and Fathers Perceptions. *Journal of Intellectual Disability*, 9(2), 155-165.

Hofstede, G. (2011). Dimensionalizing cultures: The Hofstede model in context. *Online Readings in Psychology and Culture*, 2 (1).

Hofstede Insights (n.d.). What about Singapore? *Hofstede Insights*. Retrieved from <https://www.hofstede-insights.com/country-comparison/singapore/>

Howe, D., 2006, ‘Disabled children, maltreatment and attachment’, *British Journal of Social Work* 36(5), 743–760.

IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp

- International Wellbeing Group (2013). *Personal Wellbeing Index*: 5th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University. Retrieved from <http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/index.php>.
- Jackson, Y., & Warren, J. S. (2000). Appraisal, Social Support, and Life Events: Predicting Outcome Behavior in School-Age Children. *Child Development*, 71, 1441- 1457.
- Kawakami, K., Young, H., & Dovidio, J. F. (2002). Automatic stereotyping: Category, trait, and behavioral activations. *Personality and Social Psychology Bulletin*, 28, 3-15
- Kendziora, K. T., & O’Leary, S. G. (1993). Dysfunctional parenting as a focus for prevention and treatment of child behavior problems. *Advances in Clinical Child Psychology*, 15, 175–206.
- Ketelaar, M., Volman, M. J. M., Gorter, J. W., & Vermeer, A. (2008). Stress in parents of children with cerebral palsy: What sources of stress are we talking about? *Child: Care, Health and Development*, 34, 825–829.
- King, G., King, S., Rosenbaum, P. & Goffin, R. (1999) Family-centered caregiving and well-being of parents of children with disabilities: linking process with outcome. *Journal of Pediatric Psychology*, 24, 41–53
- Kline, R.B. (2011). *Principles and Practice of Structural Equation Modeling*. New York: The Guilford Press.
- Krauss, M.W. & Seltzer, M.M. (1998). Life course perspectives in mental retardation research: The case of family caregiving. In J.A. Burack, R.M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (504-520). Cambridge: Cambridge University Press.

Lam, D., Giles, A. and Lavander, A. (2003), Carers' expressed emotion, appraisal of behavioural problems and stress in children attending schools for learning disabilities. *Journal of Intellectual Disability Research*, 47: 456-463.

Lau, A. L. D., Cummins, R. A., & McPherson, W. (2005). An Investigation into the Cross-Cultural Equivalence of the Personal Wellbeing Index. *Social Indicators Research*, 72, 403-430.

Lau, A.L.D., Chi, I., Cummins, R.A., Lee, T.M.C., Chou, K., & Chung, L.W.M. (2008). The SARS (Severe Acute Respiratory Syndrome) pandemic in Hong Kong: Effects on the subjective wellbeing of elderly and younger people, *Aging & Mental Health*, 12(6), 746-760.

Lazarus, R S (1966). *Psychological stress and the coping process*. New York McGraw-Hill

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing.

Lee, V. (2018, Apr 22). Helping kids with special needs. The Straits Times. Retrieved from <https://www.straitstimes.com/lifestyle/helping-kids-with-special-needs>

Lien Foundation (2016). *Inclusive Attitudes Survey Part 1: Views of The General Public*. Prepared by Blackbox Research. Retrieved from http://www.lienfoundation.org/sites/default/files/FINAL%20%20Inclusive%20Attitudes%20Survey%20Part%201_30May16.pdf

Lien Foundation (2016). *Inclusive Attitudes Survey Part 2*. Retrieved from <http://kidsfirst.sg/pdf/inclusive---attitudes---survey--part2.pdf>; <http://lienfoundation.org/sites/default/files/Inclusive%20Survey%20Part%202%20--%20Press%20Release%20Lien%20Fdn%20Final%5B1%5D.pdf>

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385.

Link, B., Cullen, F., Struening, E., Shrout, P., & Dohrenwend, B. (1989). A modified labeling theory approach to mental disorders. *American Sociological Review*, 54, 400–423.

López, S. R., Ramírez García, J. I., Ullman, J. B., Kopelowicz, A., Jenkins, J., Breitborde, N. J., & Placencia, P. (2009). Cultural variability in the manifestation of expressed emotion. *Family process*, 48(2), 179-94.

Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science and Medicine*, 70, 2045–2051.

Mak, W. W. S., & Cheung, R. Y. M. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities*, 21(6), 532–545.

Maroney, D.I. (2001). Attachment and the child with special needs. *The Exceptional Parent*, 10, 66–67

McFee, G. (1992) Triangulation in research: two confusions, *Educational Research*, 34(3), 215-219.

Mesman, J. M. A., & Koot, H. M. (2000). Child-Reported Depression and Anxiety in Preadolescence: I. Associations With Parent-and Teacher-Reported Problems. *Journal of the American Academy of Child & Adolescent Psychiatry*, 39, 1371-1378.

Mikami, A. Y., Chong, G. K., Saporito, J. M., & Na, J. J. (2015). Implications of Parental Affiliate Stigma in Families of Children with ADHD. *Journal of Clinical Child & Adolescent Psychology*, 44(4), 595–603.

- Miles, M.B., & Huberman, A.M. (1994). *Qualitative Data Analysis* (2nd edition). Thousand Oaks, CA: Sage Publications.
- Ministry of Social Development. (2016). *Enabling Masterplan 2012-2016*, Retrieved from [http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling Masterplan 2012-2016 Report %288 Mar%29.pdf](http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling%20Masterplan%202012-2016%20Report%20288%20Mar%2029.pdf)
- Ministry of Social and Family Development. (2011). *Enabling Masterplan 2012 –2016*. Retrieved from [http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling Masterplan 2012-2016 Report %288 Mar%29.pdf](http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling%20Masterplan%202012-2016%20Report%20288%20Mar%2029.pdf)
- Ministry of Social and Family Development. (2009). *Statistical Indicators On The Elderly*. Retrieved from <https://www.msf.gov.sg/research-and-data/Research-and-Statistics/Pages/Statistical-Indicators-on-the-Elderly.aspx>
- Mobarak, R., Khan, N.A., Munir, S., Zaman, S.S. & McConachie, H., 2000, ‘Predictors of stress in mothers of children with cerebral palsy in Bangladesh’, *Journal of Pediatric Psychology* 25(6), 427–433.
- Morris, J., Belfer, M., Daniels, A., Flisher, A., Ville, L., Lora, A., & Saxena, S. (2011). Treated prevalence of and mental health services received by child and adolescents in 42 low- and middle- income countries. *Journal of Child Psychology and Psychiatry*, 52(12), 1239–1246.
- Moran, M. (2013). DSM-5 Provides New Take on Neurodevelopment Disorders. *Psychiatric News*. Retrieved from <https://doi.org/10.1176/appi.pn.2013.1b11>
- Mukolo, A., Heflinger, C.A., & Wallston, K.A. (2010). The stigma of childhood mental disorders: A conceptual framework. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49, 92-103.

National Center on Birth Defects and Developmental Disabilities (2018, April 17). *Facts About Developmental Disabilities*. Retrieved from <https://www.healthandenvironment.org/environmental-health/health-diseases-and-disabilities/learning-and-developmental-disabilities-research-and-resources>

National Center on Birth Defects and Developmental Disabilities (2015). *Facts About Developmental Disabilities*. Retrieved from <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>

National Council of Social Service (n.d.). *Look Beyond My Disability, See the True Me*. Retrieved from <https://www.ncss.gov.sg/Our-Initiatives/See-The-True-Me/Resources>

Nosek, B. A., Banaji, M. R., & Greenwald, A. G. (2002b). Math = male, me = female, therefore math $\neq$ me. *Journal of Personality and Social Psychology*, 83, 44-59

QSR International Pty Ltd. NVivo7. [Computer software]. 2012. Retrieved from <http://www.qsrinternational.com>

Olson, C. K. (2010). Children's motivations for video game play in the context of normal development. *Review of General Psychology*, 14(2), 180-187.

Onwuegbuzie, A.J. and Johnson, R.B. (2006), The Validity Issue in Mixed Research, *Research in the Schools*, 13(1), 48-63.

Ours, L. (2014, May 21). Study explains US cultural regionalism beyond politics. *Phys.org News*. Retrieved from <https://phys.org/news/2014-05-cultural-regionalism-politics.html>

Page, S. (1997). An unobtrusive measure of racial behavior in a university cafeteria. *Journal of Applied Social Psychology*, 27, 2172-217

Parkes, J., McCullough, N., Madden, A., & McCahey, E. (2009). The health of children with cerebral palsy and stress in their parents. *Journal of Advanced Nursing*, 65(11), 2311–2323.

Paynter, J., Riley, E., Beamish, W., Davies, M., & Milford, T. (2013). The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service. *Research in Autism Spectrum Disorders*, 7, 1183–1195.

Pearlin, L. I., Morton A. L., Elizabeth, G. M., and Joseph, T. M. (1981). "The Stress Process." *Journal of Health and Social Behavior*, 22,337-56

Prakash,P. (2014, June 24). Understanding meritocracy. *Today*. Retrieved from www.todayonline.com/singapore/understanding-meritocracy

Phillips-Silver, Jessica & Aktipis, C & A Bryant, Gregory. (2010). The Ecology of Entrainment: Foundations of Coordinated Rhythmic Movement. *Music perception*, 28. 3-14. 10.1525/mp.2010.28.1.3.

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool- aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51(2), 109–124.

Power, A. (2008). ‘It’s the system working for the system’: Carers’ experiences of learning disability services in Ireland. *Health and Social Care in the Community*, 17, 92–98.

Pruett, S. R., & Chan, F. (2006). The development and psychometric validation of the Disability Attitudes Implicit Association Test. *Rehabilitation Psychology*, 51, 202-213.

Qualtrics (2017). *Qualtrics*. [Software]. Provo, UT. Available from <http://www.qualtrics.com>

Ritchie, J. & Spencer, L. 1994. Qualitative data analysis for applied policy research" by Jane Ritchie and Liz Spencer in A.Bryman and R. G. Burgess [eds.] “Analyzing qualitative data”, 1994, pp.173- 194.

Shyu, Y.I.L., Tsai, J.L., & Tsai, W.C.. (2010). Explaining and selecting treatments for autism: parental explanatory models in Taiwan. *Journal of Autism and Developmental Disorders*. 40:1323–31.

Simeonsson, R.J. (2000) *Early childhood development and children with disabilities in developing countries*. Chapel Hill, University of North Carolina.

SPD (n.d.). *Understanding Persons with Disabilities*. Retrieved from <http://www.spd.org.sg/updates/detail/understanding-persons-with-disabilities-292.html>

Stepanikova, I., Triplett, J., and Simpson, B., (2011), Implicit racial bias and prosocial behavior, *Social Science Review*, 40, 1186-1195

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd Ed.). Thousand Oaks, CA: Sage.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research. Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D., Russell, D., Swinton, M., Zhu, B. & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115, 626–636.

Richards, L. & Morse, J.M. (2012). *Readme first for a user's guide to qualitative methods* (3rd Ed.). Thousand Oaks, CA: Sage.

Ritchie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research" by Jane Ritchie and Liz Spencer in A. Bryman and R.G. Burgess [eds.] "*Analyzing qualitative data*", 1994, pp.173-194.

Ritsher, J. B., & Phelan, J. C. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research*, 129, 257–265.

Rosenfield, S., & Wenzel, S. (1997). Social networks and chronic mental illness: A test of four perspectives. *Social Problems*, 44, 200-216

Romeis, C. (1989). Caregiving strain: Toward an enlarged perspective. *Journal of Aging and Health*, 1, 188-208.

Romeo, D. M., Cioni, M., Distefano, A., Battaglia, L. R., Costanzo, L., Ricci, D., De Sanctis, R., et al. (2010). Quality of life in parents of children with cerebral palsy: is it influenced by the child's behaviour? *Neuropediatrics*, 41(3), 121–126

Romero-Gonzalez, M., Chandler, S., & Simonoff, E. (2017). The relationship of parental expressed emotion to co-occurring psychopathology in individuals with autism spectrum disorder: A systematic review. *Research in developmental disabilities*, 72. 152-165.
10.1016/j.ridd.2017.10.022.

Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: The art of hearing data* (3rd Ed.). Thousand Oaks, CA: Sage

Ryan, S. (2005) 'People don't do odd, do they?' mothers making sense of the reactions of others towards their learning disabled children in public places, *Children's Geographies*, 3(3), 291-305.

Scharlach, A. E., & Boyd, S. L. (1989). Caregiving and employment: Results of an employee survey. *The Gerontologist*, 29, 382-387.

Spratt, E. G., Saylor, C. F., & Macias, M. M. (2007). Assessing parenting stress in multiple samples of children with special needs (CSN). *Families, Systems & Health*, 25, 435–449.

Srivastava, A. & Thomson, S. B. (2009). Framework Analysis: A Qualitative Methodology for Applied Policy Research. *JOAAG*, Vol. 4. No. 2

- Tai, J. (2016, May 8). 'Your son has special needs? So do my dogs'. *The Strait Times*. Retrieved from <https://www.straitstimes.com/opinion/your-son-has-special-needs-so-do-my-dogs>
- Tajfel, H., & Turner, J. C. (1979). *An integrative theory of intergroup conflict*. In W. G. Austin & S. Worchel (Eds.), *The Social Psychology of Intergroup Relations* (pp. 33–47). Monterey, CA: Brooks/Cole.
- Tan, T. (2016, May 29). More children diagnosed with developmental problems. *The Straits Times*. Retrieved from <https://www.straitstimes.com/singapore/more-children-diagnosed-with-developmental-problems>
- Tarrier, N., Barrowclough, C., Ward, J., Donaldson, C., Burns, A., & Gregg, L. (2002). Expressed emotion and attributions in the carers of patients with Alzheimer's disease: The effect on carer burden. *Journal of Abnormal Psychology*, 111, 340-349.
- Tashakkori, A. and Teddlie, C. (2003), —The past and future of mixed methods research: from data triangulation to mixed model designs, in Tashakkori, A. and Teddlie, C. (Eds.), *Handbook of mixed methods in social and behavioural research*, pp. 671-701, Thousand Oaks, CA: Sage.
- Thaver, T., & Lim, L. (2014). Attitudes of pre-service mainstream teachers in Singapore towards people with disabilities and inclusive education. *International Journal of Inclusive Education*, 18(10), 1038–1052.
- Thomas, A., Vaughn, E. D., Doyle, A., & Bubb, R. (2014). Implicit association tests of attitudes toward persons with disabilities. *Journal of Experimental Education*, 82(2), 184–204.
- Thomas, A., Doyle, A., & Vaughn, D. (2007). Implementation of a computer based Implicit Association Test as a measure of attitudes toward individuals with disabilities. *Journal of Rehabilitation*, 73, 3–14.

Tashakkori A and Teddlie C (1998) Mixed methodology. *Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Todd, S., & Shearn, J. (1997). Family dilemmas and secrets: Parents' disclosure of information to their adult offspring with learning disabilities. *Disability & Society*, 12, 341–366

Vaughan, E. D., Thomas, A., & Doyle, A. L. (2011). The Multiple Disability Implicit Association Test: Psychometric analysis of a multiple administration IAT measure. *Rehabilitation Counselling Bulletin*, 54, 223–235.

Vaughn, C.E., & Leff, J.P. (1976). The influence of family and social factors in the course of psychiatric illness. *British Journal of Psychiatry*, 129, 125-137.

Walker, Z., & Musti-Rao, S. (2016). Inclusion in High-Achieving Singapore: Challenges of Building an Inclusive Society in Policy and Practice. *Global Education Review*, 3(3), 28–42.

Werner, S., Corrigan, P., Ditchman, N., & Sokol, K. (2012). Stigma and intellectual disability: A review of related measures and future directions. *Research in Developmental Disabilities*, 33(2), 748–765.

Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research*, 109, 265-279. doi: 10.1016/S0165-1781(02)00023-9

Wiegerink, D., Roebroek, M., Donkervoort, M., Stam, H., & Cohen-Kettenis, P. (2006). Social and sexual relationships of adolescents and young adults with cerebral palsy: A review. *Clinical Rehabilitation*, 20(12), 1023–1031

Wong, P. (2015). A cultural–historical model to understand and facilitate children's development. *European Early Childhood*, 23(5), 645-661

Wong, C. C., Mak, W. W., & Liao, K. Y. H. (2016). Self-compassion: A potential buffer against affiliate stigma experienced by parents of children with autism spectrum disorders.

Mindfulness, 7, 1385–1395.

White, M. J., Jackson, V., & Gordon, P. (2006). Implicit and explicit attitudes toward athletes with disabilities. *Journal of Rehabilitation*, 72(3), 33-40.

Wright, S. D., Brooks, D. E., D'Astous, V., & Grandin, T. (2013). The challenge and promise of Autism Spectrum Disorders in adulthood and aging: A systematic review of the literature (1990– 2013). *Autism Insights*, 5, 21–73.

Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52, 30-41.

Zimet, G.D., Powell, S.S., Farley, G.K., Werkman, S. & Berkoff, K.A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 55, 610-17.

Appendix 1

Factor Loadings for Exploratory Factor Analysis

1) Factor loading for Three-Factor Model (Scale of Attitude towards Disabled Person (Implicit Prejudice))

<i>Items No.</i>	<i>Item Statement</i>	<i>Factor Loadings</i>		
		<i>Component</i>		
		1	2	3
Q20_4.1	Adults with developmental disabilities are in many ways like children.			.501
Q20_6	I agree with the statement. “People with disabilities should be given more control in making decisions that affect their lives”.		.618	
Q20_8	I generally feel sorry for people with disabilities.			.724
Q20_12.0	People with disabilities can be expected to fit into competitive society.		.689	
Q20_13.0	People with disabilities should be allowed to live where and how they choose.		.727	
Q20_14.0	People with disabilities are more emotionally maladjusted than the general public.			.576
Q20_15.0	People with disabilities are able to adjust to life outside of an institutional setting.		.682	

Q20_16.0	Laws to prevent employers from discriminating against people with disabilities should be passed.	.711		
Q20_17	Simple and repetitive work is appropriate for people with disabilities.			.653
Q20_18	The presence of a disabled in a social gathering makes people uncomfortable.	.540		
Q20_20.0	The opportunity for gainful employment should be provided to people with disabilities.	.772		
Q20_22.0	People with disabilities are a financial drain and give little back to the community.	.733		

Note: Factor loading of items above the .40 cut-off level are highlighted in bold

2) Factor loading for One-Factor Model (Affiliate Stigma Scale)

<i>Items No.</i>	<i>Item Statement</i>	<i>Factor Loadings</i>
Q24_3.0	The behaviour of my family member with developmental disability makes me feel embarrassed.	.742
Q24_6.0	I worry if other people would know I have a family member with developmental disability	.739
Q24_9	My reputation is damaged because I have a family member with developmental disability at home	.801
Q24_10	People's attitude towards me turns sour when I am with family member with developmental disability	.771
Q24_11	Having a family member with developmental disability imposes a negative impact on me.	.761
Q24_13	Having a family member with developmental disability makes me think that I am lesser to others.	.787
Q24_14	Having a family member with developmental disability makes me lose face	.851
Q24_15	I avoid communicating with family member with developmental disability	.762
Q24_16	I dare not to tell others that I have a family member with developmental disability	.824
Q24_17	The behaviour of family member with developmental disability makes me feel embarrassed	.752

Q24_18	Given that I have a family member with developmental disability, I've cut down the contacts with my friends and relatives.	.776
Q24_20	I've cut down the contacts with _____ (name of family member with developmental disability).	.754
Q24_21	I dare not to participate in activities related to developmental disability lest other people would suspect that I have a family member with developmental disability	.858

Note: Factor loading of items above the .40 cut-off level are highlighted in bold

3) Factor loading for One-Factor Model (Family Questionnaire)

<i>Items No.</i>	<i>Item Statement</i>	<i>Factor Loadings</i>
Q25_1	I tend to neglect myself because of him/her (person with special needs).	.673
Q25_4	He/she irritates me.	.682
Q25_9	When something about him/her bothers me, I keep it to myself	.635
Q25_10	He/she does not appreciate what I do for him/ her.	.582
Q25_11	I regard my own needs as less important	.602
Q25_12	He/she sometimes gets on my nerves.	.738
Q25_13	I'm very worried about him/her.	.669
Q25_16	When he/she constantly wants something from me, it annoys me.	.728
Q25_19	I have given up important things in order to be able to help him/her	.728
Q25_20	I'm often angry with him/her	.743

Note: Factor loading of items above the .40 cut-off level are highlighted in bold

Appendix 2

Themes identified from caregivers' response for face-to-face semi-structured interview (N=21)

Themes	Subthemes	Categories	Example quotes
Theme 1: 'Me as a child': the pre-existing knowledge of caregivers	Singapore society in the past	Different label for NDD condition	<p>Cheryl: Society very different only recently more of these cases. Probably last time the children are called introvert and you don't really talk to children like that. Those extroverts they will speak a lot so probably we are more drawn towards the extrovert, which are called the popular crowd. There's always the popular crowd and introvert which people say hey she's strange don't talk to her quiet. Because now with I don't know medical knowledge a lot of children are being classified as autism group.</p> <p>Maple: my era is worst 30 plus years back who will know...last time we don't know...like my mum say they are ti gong kia...I also don't know why they say is ti gong kia lah...back then they don't know much also can led a life</p>
	Personal Knowledge	Limited exposure and interaction	<p>Pang: I think I had some knowledge but not a lot...i mean I was aware like okay there was this term...so the kids very active and all that...but</p> <p>Cheryl: No, Firstly I had no interaction with people that had autism and childhood that time was like ...I don't know that was 20 or 30 years age. Society very different only recently more of these cases.</p> <p>Candy: I had experience to work for some kind of this kind of, like mentally handicapped children in japan. They are very familiar like autism but very seriously and mentally handicapped and the intellectually handicapped people. So it is very natural for me.</p> <p>May: They are kept at home... they are hardly exposed hardly see them outside...they go to those special schools but we have never seen them...we have not seen them independently they are all kept at home, they are at the hospital, or they are erm just don't see them...</p> <p>Kate: No you hardly see them...you hardly see people with special needs...again during my childhood I don't remember seeing anybody</p>

			<p>...not with down syndrome luh but with cp ...what's that...cerebral palsy because I have got a classmate with CP. Because they are normal is only their disability is mobility...as for down hardly you see them at all...as I say I think last time if it's down or anything they all keep away they do not want to expose</p>
	Personal Knowledge	Restricted knowledge/ wrong conception about NDD condition	<p>Kate: Autists tend to be a bit loud and everything and during that time we don't understand them...</p> <p>Anne: Ya but now I see mostly because I did take transport to school last time...I see a lot of normal faces arh, cannot tell that they are children with special needs but they indeed have special needs.</p> <p>Krystal: because at that time I thought that ASD is as long as you got no eye contact, you will laugh you will play peek a boo means he is normal, he got eye contact and he is happy with peek a boo and all that. So when he was few month old to 1-year old I didn't suspect anything wrong with him is very normal. In fact he was in infant care you know when he was small that time he play with his friend leh. I was like how come arh. Then my brother told me that even that when he pay with his peer at very age, after that he can still change one to become ...then I'm like huh like that one arh...then they say those that don't like to look at himself in the mirror are autistic right...he's okay leh he laugh at himself in the mirror he is very happy so I thought that everything is okay lorh. Then I got to learn about something new about ASD also, that means there is no hard and fast rule that if there is eye contact or if he see himself in the mirror or he like peek a boo that means he is normal, may not be. Because ASD is a wide spectrum.</p> <p>Valerie: I think another thing with kids with ADHD is that they are so used to being told off.</p>
	Attitude towards individuals with NDD	Implicit prejudice	<p>Pang: I'm quite open you know...i don't think you know special need kids you know...I don't see them as like hopeless. ..you get what I mean...because I think that everyone have erm you know have their</p>

			<p>own strength and you see that there are people with special needs that can succeed in life .</p> <p>Penny: But they really learn a lot of things lah they mix...but cannot mix with normal children...don't know what they are talking aiya they have no patience...</p> <p>Jamie: but I feel is also depends on the child condition...like you say ADHD I think is really very difficult to control them it can be really annoying so no choice have to get out of the house leave it to the maid</p> <p>Krystal: Frankly speaking I was initially aiya he got an autistic nephew arh should I marry him you know because I don't know whether is genetic a not some say is not some say it is, so I also don't know</p>
	Attitude towards individuals with NDD	Pity	<p>Anne: I feel that they are pitiful...sometimes when I go out, I see their parents carry a lot of stuff need assistance I will go up and help as I feel sorry for them....that is how I feel...</p> <p>Ashley: erm okay initially I feel pity for those lah, especially those who really need, how to say arh, cerebral palsy and those who need total care, round tube feeding all those.</p> <p>Elise: i also feel that it's hard for me to accept to see kids of erm various erm what do you call that...erm special needs lah ya..I actually feel very sad lorh...sorry</p>
	Attitude towards individuals with NDD	Empathetic	<p>Amber: Generally, I guess because of my personality and character, I will definitely try to have some empathy have a soft spot lah definitely or these kinds of children. I mean after all, they are a bit how to say, I meant they are not like a normal child, so they probably need ore support ya so for me I would lah</p> <p>Krystal: but now like I know ASD child sometimes on the street or on the MRT I will I think he is you know...you will kind of know and be a bit more empathic towards them ya because is really not easy for the parents in public...sometimes when they have a meltdown aiyo is (tsk)</p>

	Attitude towards individuals with NDD	Apathetic	<p>Sandra: See them around but don't care (laughter) I never expect I will get a down syndrome child you know what I mean a not.</p> <p>Jamie: I'm aware but not really into it...</p> <p>Pang: Ya I know these kids you know...ya I didn't give much thought about it</p> <p>Amber: Even you just walk along the street, how many people really know what autism is. I myself don't know what autism is until I have a son who is autism. And looking at my background, I am an educator, I am educated is till don't know right? Until there is a need to, I am being forced to know then I go and know lorh. So what about normal layman. I think basically, they are much the same like me, I am the typical layman people. I mean if I I don't have a contact with people with special need, I probably don't even bother about them.</p>
Theme 2: "Me as a caregiver" the caregiver role of individual with NDD	Caregiver Role conceptualization	Provision of nurturing environment	<p>Valerie: I mean obviously, any parents, my views about parenting generally not just parenting children with any social learning disabilities but your job is to let them fulfil their potential be the best that they can be, irrespective of any disabilities and talent, any skill. They are who they are. They are not a blank slate. A parent doesn't create a fantastic human being. You get what you get and yes you provide an environment, but it has to be a nurturing environment, and I think you need to get them to try and get them as independent as they can be.</p> <p>Krystal: A child can feel whether he is being in a good environment a loved environment a not and parents actually play an important role in the sense that erm is a loving family you know parents you know like don't quarrel that much that kind of setting I think we are in this kind of setting lah (laughter) you know give them a good environment this is very important.</p> <p>Ashley: Erm my role as a caregiver to nurture her lorh so that she can be independent and then able to contribute to the society lorh.</p>

	Caregiver Role conceptualization	Role as an educator: academic concerns and imparting life skills	<p>Cheryl: so the role of educator but it is not easy because I'm performing the role of a mum...suddenly I'm educator don't want to do say suddenly why my child do this..yes yes so it's not easy</p> <p>Sandra: Whereas he can dance, he can do those things emphasis on those things but now main thing speech. My target is speech and mind, the brain</p> <p>Pang: Now they are not like toddlers I mean they are like they can interact so they need more and more of my care in terms of their like learning...as in like reading books...</p> <p>Candy: Erm...education? Ya. Is to educate her the important things in her life because we adopted her her very old age the late 40s so we cannot be around with her until she is 40 years 50 years old maybe we will die much earlier so we want to pass her values and experiences and knowledge as much as possible to her. She needs to get such kind of knowledge in school but at home, we want to teach her how to survive this society and then how to behave as a good person as a good Christian and to pass erm experiences ya</p> <p>Penny Erm after all, the most important thing is to think by herself. Thinking by herself and then to decide, making decision by herself and then to organize her life by herself. That kind of, I mean the, the one word is willpower. The grit</p>
	Caregiver Role conceptualization	Encourager/ Supporter for child	<p>Cheryl: Okay besides the basic role right getting the kid dressed hygiene feeding them...right now my role is much more than this...I become like their supporter, encourage them teach them stuff ya ...</p> <p>Penny: I want to encourage her to overcome these kind of problems and then I always say erm...to express my love to her</p> <p>Pang: you know so I'm a bit like counsellor...you know and I have to tell him over and over again you know...then he will like okay alright...so I have to show him videos sometimes you know...people...to motivate him like you know nick for example...</p>
	Acceptance process	Discovery of NDD condition	<p>Pang: then I brought him to a psychologist that actually confirmed that he has ADHD, and he also has some learning disability as well...</p>

			<p>Elise: of course people have been telling me aiya my friend who who who 4 years old also cannot the after that okay already you know that kind of stuff...then we've been sharing a lot of such things luh...so that's when after that subsequently I went to the doctor and then it's suspected autism..</p> <p>Amber: so I do have training about related to early childhood development, so it helps me to actually identify my boy. Because I was relapsing that he was abit different. He is also different form his elder brother and also, I learn about the importance of early intervention. Ya, so that's why when I first learnt that he is, in fact very interestingly, I realize that he was playing by himself and he is not verbal even when he is close to 2 and so I, I went to go and search online and found out that all erm, all learning, all autistic children would have learning disabilities but the other way is not true. So it was an alarm bell for me then I happen to find this American autistic checklist on the website. I don't know lah I think so. So I just do a preliminary check and the result is that this boy is high risk of autism so second alarm bell. So that's why I quickly went to polyclinic for referral to KK then I told my doctor I suspect my boy is autistic. Then my doctor says okay, so I will refer him to this child development unit in KK and then from then on, the support is there.</p> <p>Cheryl: Yes exactly my son is ...i believe he really is ...although I don't want him because it took me quite a long time to really to see a doctor because I wanted to monitor more...now I see children getting younger like 1 2 year old to get...being classified.. or parents probably.</p> <p>Ashley: Actually for this part, I can tell. When I know my daughter had GDD is about 3 and a half years old diagnosed ya. I know that she is slow but we didn't know she got this global developmental delay until we bring her to a child development in in NUH then they diagnosed her about this.</p>
--	--	--	---

	Acceptance process	Sad and in Denial	<p>Pang: so when the psychologist confirm it ...although I was mentally prepared I was still very sad...is like why...you know something like that...so it was very difficult to accept..it took me also quite some time you know...</p> <p>Sandra: So I was depressed. Who not depressed right. After 18 years come out a down syndrome boy might as well don't come out right so that's it lah. So he came out down then I was disappointed and got angry with God then I got a lot of problem really neighbor, with my husband wah really went to depression already that kind.</p> <p>Jamie: Initially I didn't really accept it I was like going into depression</p> <p>Elise: because okay all parents arh who have erm who went to a doctor and have been given such an information would go through a stage of denial like even for me I went through a stage of denial...so I think for her at that point of time when she went to the doctor and she got that information...she was also at the time of denial ...so during that period of denial its actually quite hard to accept advise luh ...of course you will still listen but you may or may not do it...</p> <p>Krystal: Actually, initially arh my husband also denial stage eh he say no lah where got like that all those...</p>
--	--------------------	-------------------	---

	Acceptance process	Ambivalence of caregivers about accepting NDD diagnosis of child	<p>Elise: Actually even for me hor I do not know if I fully accepted (laughter) ya I do not know whether I fully accepted luh...because there is actually progress in her there is actually improvement...of course there is something is your heart that you feel hopefully she's not but of course...I mean with the still persistent eye contact issue I feel that probably she still is luh but hopefully not to bad that kind...so I think to a certain extent you will constantly be going through the acceptance-denial then going back and forth you know that kind of stuff...</p> <p>Jamie: Actually I'm not 100% accepting yet is like maybe 80%? (laughter) ya then 20% is erm you know there are still friends of mine still doesn't really know about my child's condition and I have not shown them any photos all that...some of them will just ask me eh how come you are not posting any photos in Facebook and all that...then I will just brush through and say that no lah I don't want him to get kidnapped posting all the photos all that then they will just laugh out loud ...(laughter) and I will just change topic all that...</p> <p>Pang: You cannot wish that he wasn't like this...so you have to accept him and work forward rather than...a lot of people I think they regret... you know maybe I didn't eat well or I didn't do this...why is it like that...you know they keep ...they cannot move forward you know because you have to move forward you have to accept that yes it is like this...and then we work...move forward...you know and think like you know how do we best help the child ya...so instead of lingering in you know like in pessimism and negative thought then you have to think positively...</p> <p>Victoria: Yes because the mum has given birth the mum is the caregiver. Mainly the mum is the one who bring her own child for immunization, so the mum is the best person to be aware of in a way whether the child is special or not. If the mum herself cannot accept, who on earth can accept your child.</p>
--	--------------------	--	---

			<p>Maple: Ya lah if not how you going to help them you are the one who going to suffer leh if you cannot accept from day one you don't accept when they are older they will develop worst and teenage time develop into some like mental issue then isn't it that you suffer more meh?</p> <p>Sandra: You have to learn acceptance that is your child got no choice</p> <p>Kate: First thing they must accept lorh...they have to accept whatever condition child is in ...only if they accept only once they accept his condition then would they be able to care and move on...if you don't accept that child...you will just back off to everything as well.</p>
	Objective caregiver burden	Financial concerns	<p>Amber: Financially, I think it is quite a strain lah because I also have an elder boy, I also have to meet his needs. But so far, me and my husband we are trying to manage lah. That's why we have to working. I mean our idea is if I don't work, our resources to support our 2 boys will be very limited</p> <p>Tom: Then she is seeing about 7 8 specialist you know and is not cheap</p> <p>Maple: like the PCF during that time when I still don't know anytime they do share with me thing...this is when I got to know like actually swimming lessons also got special needs...but expensive lah ,...back to square one is all about money lah...but just that the school can also provide support</p> <p>Sandra: Now arh, 150 for 1 hour...1 hour hor not 1 month hor. Cannot afford it moreover they tell you your son I s20 cannot learn speech already but when he was young I should have send him lah...I save the money save the money until now I regret. He can't talk because no therapist when he was young</p> <p>Elise: and I mean personally I felt that the school fees is pretty high as well...i mean I could understand probably is the ratio that they need because of the special needs kids...ya so it's like...like for example right now right...my preschool I'm sending her 5 days a week I'm paying 400plus after the subsidies lah but for rainbow I'm paying 700 per month...ya and there's no subsidy because of the income range</p>

			<p>lah ...which I felt that is also pretty high...even...I mean my income range is not like super high so ..</p> <p>Sanders: Over here, if parents want to go to the government there is waiting list there is 30 dollar per hour and if you get that is once every 2 weeks I you are lucky if you go to private is 120 or 150 dollar per hour and the prices keep rising so that's one thing.</p> <p>Anne: The school fee is very expensive because we are PR but there is no choice lah these kind of things...</p> <p>Cheryl: Ya long waiting list and if there is private too expensive. yes so uhm ya. Resources are there but it doesn't mean I can have quick and easy access to them. Time... waiting time, financial. Ya.,and sometimes lack of manpower in those places like subsidized place so ...ya...or maybe not even experience people to train</p>
	Subjective caregiver burden	Dealing with emotional inconsistencies of NDD	<p>Pang: but there are some days. there are really ups and downs like he is not very consistent...in some days he is very good...he will do do very quickly he will listen to you...but sometimes just you know when he get up and he just doesn't want to do things...he will like keep wanting to take my phone and just immediately switch on the tv...so is really not consistent... some days he's good he complies he listened and some days he is not...i think dealing with these inconsistencies.</p> <p>Elise: for example in the morning...i think it happens to all kids lah...so sometimes they get moody they don't want to get changed and things like that...so now what I do in the morning I will actually play music..</p> <p>Cheryl: The challenges is more of getting them to sit down and finish the meal don't run up and down in public places like restaurant because when they are excited they will show their excitement like the kind of noise eeee these kind of laughing sound ya because ya I think socially some people may not like it because the volume of the voice may be loud too rowdy or they can't wait like when they are done they have to go but some of the family are not done yet. So Waiting is tough and getting them to sit down and complete task or to eat ya and</p>

			<p>what else...erm ya mainly these..oh an the meltdowns ya he he when I say no you can't do this they will be like very resistance towards it</p> <p>May: sometimes we are at loggerheads he wants ice cream, but I tell him you know what ice cream will do? He will have the lumps but he insists and then suddenly he will...when he was younger he used to lunge, lunge out of people, scratch them or you know and then is...is very difficult</p>
	Subjective caregiving burden	Need to be patience in repetitive teaching	<p>Pang: Erm challenges arh...I think the patience lah you know...</p> <p>Victoria: The down days are when I got no choice but to lock him up in a room you know I have to let him scream and cry...i even have to go through the stage of pasting mahjong papers everywhere you know in the whole room you know through all the big crayon and pencil just to make him right</p> <p>Suzy: Learn that there's no book or guide that can follow; have to do everything from waking to communication (trial and error)</p> <p>Tom: ya, that method, sometimes work sometimes doesn't work...And you can hard or you can use the soft...is very difficult so it depend on situation lorh</p> <p>Candy: So it is very tough to be patience, must be patience all the time...</p> <p>Cheryl: Its tough its tough really sometimes I just feel like do some kind of you know reaction like smack backside and stuff I tell myself must keep calm it is not easy because we also feel frustrated and when we are frustrated we take to want to take the easy way out right</p> <p>Ashley: Time out first let her both of us cool down first. I say we don't do today tomorrow then we do.ya because she frustrated I also frustrated nothing can be done.</p> <p>Penny : must be very xi xin...ai xin nai xin xi xin...ai xin do a lot for him...nai xin...repeat and repeat...xi xin must look at them how come they walk like that how come no appetite there is something wrong with them already because they can't tell you...look into it..the 3 xins towards them..ai xin the most important</p>

			<p>Penny: you must have a lot of patience a lot of love...I still think love is very important ...irrespective of anything luh even aiya parents lah husband and wife also if there is love arh definitely you will do the upmost luh...no love do it as a role not willingly, on the way you do it lah but out of the way you won't do...</p>
	Subjective caregiving burden	Public attribute blame to parents for behaviour problems of individuals with NDD	<p>Candy: Yes and especially you know ADHD it is very tough and during her nurse kindergarten days, a lot of parents complain about her so actually she was kick out twice from student-care the child-care centres so every time we had to seek for the new centre ya...so it was quite tough</p> <p>Sanders: I know it's hard and it is an unpleasant and difficult reality being a parent of an autistic child because you know why...they don't look like they have special need a lot of time so this is very difficult for the parent sometime they are please can't you just get it all together or sometimes when it is right in your face is like I can see right but with an autistic child you know</p> <p>Anne: children with specials need it is not that you never teach but it is that when you teach them they don't understand...arhh...and their behaviour is a bit different from typical child...so sometimes their behaviour when you are outside you see them behaving like that...some parents , parent of typical child they will think that it is the parents poor upbringing that result in this child to be like this...they will have such thoughts...if you educate the child properly, the child shouldn't behave like this...so I feel that it is difficult because the typical child behaves well...when you tell them not to behave in this manner, they will listen. You ask them to sit down properly, they will sit down properly mah. But because they are not aware that special needs child are not typical child, especially autistic child, their behaviour and attitude is a bit different.</p> <p>Kate: don't label as the parent are not looking after the child...i mean the parents are also in a dilemma...i mean they tried everything to help the child but the child is born with this syndrome...there's nothing</p>

			much she can do lorh I mean she just have to try but if the public don't see it that...of course the caregiver will also be very hurt
	Subjective caregiving burden	Affiliate Stigma (Conceal child's condition from others)	<p>Valerie: he's pulling so he was having trouble eating, it was recommended that we have speech and language therapist, oops sorry speech and feeding therapist. I laughed right because I just thought, I can't tell my any of my friends in England because they will just laugh at me.</p> <p>Candy: Sure (affirmative tone) but the teachers have problems and they have other students and if they focus on our daughter then the other parents will complain about it right. So we need to compromise. If I were the other kid parent, I really hate these kind of kid all the time disturb our daughter or our boy. So is kind of we do up to this certain, up to this point and then please compromise to a child as well. That's our attitude</p> <p>Krystal: Ya is bright is not dark is bright and then there is an area for them to walk around whatever and some of the kids walk around and the parents are okay because all their kids are the same so they won't get that kind of embarrassment quite good hor I think is somewhere don't know what poly...I can't remember just last week only In the news</p> <p>Elise: early intervention center does it mean that she is...would people look at her in a different light...okay in the morning the principal is very nice because I told her is quite a hassle because I have her uniform there and after that change her uniform back...so the principal is quite nice to say that actually you can let her wear her rainbow uniform to school...but I made the conscious decision of not letting her do that...because I do not want her to be different from the other kids and I also do not want the other kids to say why is she different from them</p> <p>Anne: for me when I bring my child out , unless there is heavy criticism I will keep quiet...if people heavily criticise me and say I</p>

			<p>never bring my child up properly,... then I will say sorry but my child has special need he cannot control his emotions I will explain to them lah... usually when there is no heavy criticism and they just speak behind my back, usually I will just ignore... I don't know is it just me a not lah... this is me lah if you just speak behind my back or never direct speak to my face, then I will just ignore lah... of course I don't feel good and feel unhappy but just...</p> <p>Jamie: you know there are still friends of mine still doesn't really know about my child's condition and I have not shown them any photos all that... some of them will just ask me eh how come you are not posting any photos in Facebook and all that... then I will just brush through and say that no lah I don't want him to get kidnapped posting all the photos all that then they will just laugh out loud ...</p> <p>Pang: erm general let me think actually for his case because is quite mild a lot of the parents actually don't even know he has.. you know ya... only like my close friends... like church friend ... then they know that he has... you know... but he is still able to mix around with other kids ya..</p> <p>Tom: okay I may want to say that there a lot of parents who do not want to bring their child out. Why? Maybe they think that it is cumbersome, troublesome. Erm they also feel that if let's say the child misbehave how are they going to react in the situation. Like for autistic child if let's say they are sound- sensitive if they go to a place that is very noisy they will have meltdowns also like even down syndrome have meltdown so is how they react to the situation and in the public area you see. That's why sometimes people dare not bring their child. But for this one arh, we have no choice, we have to run our errand we have to do our grocery so we have to bring her out</p> <p>Sanders: I really felt that the pressure of living in Singapore for me and controlling.... me controlling his behaviour especially in public here had been very vey bad for me. Or I was controlled when no one is here. It was like he would do this you know mrt right you sit like</p>
--	--	--	--

			<p>that...right how you walk all these people...ooh you bump somebody...</p> <p>Sandra: Because you see, the person with the biggest impact on the autistic person perspective is actually how the parents feel about them. But how the parents feel about them is very much affected by how the public react because if I am on a holiday where I feel relax about him which is why I want to stay away from Singapore.</p>
	Coping mechanism	Support from school	<p>Tom: A lot of trial and error and we really appreciate the teacher in the school and psychologist in the school. We actually communicated well. They actually erm erm gave us ideas as how to cope. So we use a lot of method. So not really one is really good, so we are still trying lah. So what we are doing now is we give her time-out. Let her shut down then maybe 5 10 minutes then come back. Then she will be okay. Then after that she will be okay lorh</p> <p>Ashley: teacher help ask educational book then we explain to her she keep asking why got discharges red color. I say every girl will eventually have this one so the teacher also help to reinforce to her lah so remind her to go toilet and change lah</p> <p>Kate: homecare teachers lorh.</p> <p>Victoria: so I will actually communicate with the teacher in a way that if there is any issue or anything that they have to highlight they will text me so I'm actually working in a very closer relationship with the school and at home when he is back.my caregiver will you know prepare his meals.</p>
	Coping mechanism	Friend support	<p>Jamie: ya definitely ya...so is like erm friends can you know we don't talk about babies luh we don't talk about our child we just talk about some other things like when there is good deals or what ya then we talk about that...at least something to occupy me rather than doing the same thing at home...something to redirect me lah something fresh...ya and for family would be like support from them lorh then sometimes they will come over and visit him ya then there's somebody around luh because most of the time I will be alone</p>

			<p>Tom: Because for us, we are here, we speak to other parents also then we learn from the experience of other parents how they handle the children like for her she is a girl, she goes through puberty and all these thing. I actually learn from other mummies how to deal with her how to guide her on when she has menses those kind of things...so in always we share the knowledge</p> <p>Maple: I did recommend my this school to some of the group then they were saying that but some of them say that it is too far...I tend to share lah sometimes I see what they post then I tend to share...but how come you came to know this group?</p> <p>Jane: Social side ...if the mother have this type they must have a support group like they have a ...last time we have a support group arh they have a somebody in charge of this team group...every month they have a group support bring the child here talk and then bring some potluck food for them</p>
	Coping mechanism	Physical punishment	<p>Maple: Sometimes I don't know how to manage lorh because I don't know what his problem I just ignore sometimes I ignore sometimes...for me I believe in caning but of course not that kind of harsh luh...just use the cane just like scare him like that...</p> <p>Krystal: Use the cane to cane him (laughter) okay lah I think patience one thing secondly is when you try to understand your child I think he will also gradually know that you are trying your effort to understand him to get into his world so gradually he would or she will also open up ya...</p> <p>Penny:no lah for me I won't do that but must have a lot of patience lah they don't beat this type of children but I will beat Brandon when I teach him last time in school on paper roll up lah adding use the hand lah but they are very bad at maths very difficult arh....so I just like that lorh so he know that you must study lah you cannot say anything anything that goes wrong I will punish...</p> <p>Sandra: I cane until 12 then never cane already then he very guai. Eh play a part eh...beat...I beat recorded ...now I never beat him but he</p>

			<p>is very guai but I beat him when he is very naughty lah but now no more already because I told my husband I have to look after him personally, if he is naughty I need to cane. Even the bible say spank the child if not you spoil him. But by 12 I don't cane him already, in fact when he was young he even took the cane and throw it downstairs(laughter) he throw my cane downstairs I got to hide the cane imagine that and then he look at where I keep the cane then he threw my cane downstairs. But now as he grow old, he is very guai now one look he looks we are angry. So I believe when young arh, have to discipline. If don't discipline, once he come to a certain age arh when he is stronger than us arh we cannot control them.</p>
	Coping mechanism	Adjust expectation required from child with NDD	<p>Maple: Not good lorh because uhm hard to accept every parent want their kid to be normal what ...but then we told ourselves that to him we have to be more patient and also we have to try to lower our standard ...like I'm really prepared like lower my standard of his academic because we really he can cope...I'm not going to send him to mainstream school...</p> <p>Pamela: You have to realize yourself then alter when I have this child, when I was carrying her, I know that she is a down. I was telling myself, I said that (pauses) I...I will be dealing with something who is (pauses) who needs help whereby I have to change, right. I said that, you know is not easy but if you look at my daughter right now, she looks like a typical child because if later I show you her photograph, you can see the transformation 360 degrees.</p> <p>Sandra: I'm not going to do. I say I scream at him everything cannot do leh I say I don't want to scream at my son already. Don't give him already I don't bother about homework so I think they also stop giving homework. I say he get all right because I teach him you know, not that he knows you know. If he can do by his own, I don't mind but every month, give me problem sum I got to read. Read already in the end I end up screaming at him I say forget it lah. In the end is me who</p>

			<p>do the question then go back all correct correct. Eh mummy do eh.i say, I don't pressurize him just forget him.</p> <p>Ashley: No no no she frustrated until she say she cannot focus already ya she cannot do means she cannot then I don't force her just put aside. No point forcing her then she how to ay will be next time if I give her I mean teacher give her the same worksheet in school she also breakdown in school so many sets teacher give her then I ask teacher cut half lorh. Instead of 10 give 5 will do because she see so many pages she already no confidence to do already. Ya</p>
	Coping mechanism	Self-help(emotional regulation)	<p>Sanders: I could feel my feeling are like angry I'm just like god I'm frustrated I'm angry say come on already. I'm trying to say ok I acknowledge your sadness whatever let's move on but that no...okay not good enough you reach out this way...so I went into my room I started to write. Started to write about whatever something else just take my mind off of it</p> <p>Pamela: Correct, that's why my sister was telling me. She says luckily you can outwit your own child. Sometimes when people ask me, eh how come you, still got the energy? I said I because of her that's why I have to, I have no choice. I have no choice I cannot be slack. I have always to be ahead of her. I sometimes I can be quite blunt to parents I say you know what, don't be guilty. The minute you are guilty that you give birth to the child and then you spoon feed the child, you are doing them a disservice.</p> <p>Sanders: It seems very corny but fundamentally, do we really know how to give unconditional love. But how far can it stretch the unconditional love. Is not easy it can strain you to the limit then you have to ask yourself, how do I love this child. How do I love him in the most positive that is also good for him and also good for me to the point where you were asking how could I move him right?</p> <p>Anne: Ya cry everything out till my heart's contentthen mediate a while...but there's no choice...emotionally I still don't feel very relaxed that kind but now when I see him and observe his</p>

			improvement at least he can walk now, can eat now , he doesn't need a tube...slowly, slowly my emotionally I'm feeling better...
	Coping mechanism	Self-empowerment (read up)	<p>Elise: we definitely do not have the information or knowledge to help them enough I think ...of course for myself I've tried to read up on my own and things like that...I mean it helps...</p> <p>Anne: Erm for me, I surf the internet and sometimes I find information that is helpful for ...I see most information about autism and then I will try out these methods on him...I feel that the methods do help as I see some improvement in him then I will share with friends or my online friends... I will send the link to them and share with them...autistic information shared with fellow parents of autistic children because others condition may be different from autism...we try our best to share information</p> <p>Sandra: Now with the internet I can source thing sand I read ...one thing about me is read then I think how to improvise like they say gym exercises ...</p> <p>Pang: just research with the experts. And SPARK is a great resource actually.</p> <p>Cheryl: I mean you have to I cannot sit there and let the time pass away because this is the time where I...this is like a medicine. Time is like a medicine for them I have to make use of resources. Whatever I have to help my child and also the normal child I cannot leave him. Because still need to prepare him for primary school... actively looking out this...</p> <p>Jane: not that good lah I also different type of scenario lah so they give talk and then they some of them they give talk how they improve themselves so I also listen lah...then after that tend to understand a bit more...</p> <p>Tom: Research lorh. We googled then I think also because we are members here so we have talks all these we come and attend. Then okay, when erm ...before she was born she was already on waiting list to go EPIC.</p>

			<p>Anne: you give born to this kind of children there's no choice you have to stand up and help yourselves...if you cannot even help yourselves, then nobody can help you lorh I feel...even you go to the doctor, ask them they also cannot rally help you...the only way out is for you to help yourself...source for information by yourself online...</p> <p>May: I would say that erm...take it as a challenge because you want the best for them so you need to handle it yourself then you see to it that it works for them...I mean you are the manager of the person so whatever he needs you would have to think that this is good or you get yourself educated also because we are not equipped...when they are special we are the mum... are we equipped with knowledge on how to manage so get yourself equipped with that and keep ourselves updated because your theory can change like ooh maybe this is better this way is better so change...put yourself in the you are able to change your mod change your capacity don't be run down by work and you leave the management to the maid you know don't do that...actually then you only get I don't know ..tips may work out or may not work...so plan that you want to go far overcome the obstacles that he has...then manage him well you know take that challenge to change yourself first change the situation make yourself work with the child then later when you see that they are ...</p>
	Coping mechanism	Religion and hope	<p>Pang: but maybe I think because I'm a Christian so like I believe that erm you know...that he does not ...that he was not born by accident you know there is a purpose ...there is a purpose in everyone's life...so is my job as a parent to guide him and to find the purpose of his life...</p> <p>Pamela: Through the grace of God I say because at that point mummy really cannot I have one doing PSLE and this one like that.</p> <p>Penny: I say anyway I leave you to God also I always pray luh I say God you are great...</p> <p>Cheryl: That time erm...we do go to church luh...church members that erm...will pop in to see her and talk...so ya...</p>

Theme 3: “Managing my Multiple roles	Managing caregiver role for more than one child:	The role of education and provision of equal time between children	<p>Penny: Parents must teach their own sibling how you see of course don't ask them to look after them depending on themselves also this one cannot be force one...depends on the child life...destiny the minute you are born...</p> <p>Amber: I try to encourage to my older boy and I also try to explain to my older boy that his didi is special. I even borrow library book to read with my older boy about living with autism, so I try to get my boy's understanding and also as he grow older, I think is the different phase of his life.</p> <p>Pamela: It depend you know. The most important thing is when they were young right, you have a special need child but then remember the other child is a typical child but that one is still a child. The minute you burden that child for this child, resentment will grow and then the minute they get older, they will hate that child they will hate the sister</p> <p>Krystal: Hopefully lah but my brother erm he got 3 children 2 daughter 1 son the son is autistic the 2 are normal. Then the eldest daughter now primary 3 primary 4 so she recently already that her brother is autistic then when I think last year also got the outing then the brother got a bit of meltdown lah then she told me lah he is autistic then I'm like ooh she understands she is like primary 4 then I think she accepts that the brother is like that. So is also ya I think the sibling part is also important to educate them that ya to accept and to.</p>
	Managing caregiver role and career	Prioritize needs of caregiving for child with NDD	<p>Kate: Ya ya ya because I am still, I own a small company here and I have some business in japan but I want to do the business, conduct my business more aggressively but because my income is not so much now so I need to do a lot of housework as well and also because we wanted to outsource her study as well but most of them cannot take her.</p>

			<p>Elise: usually by 6 plus 7 we have to pick her up...so is actually quite challenging lah for us...so if I cant make it my husband has to be the one who has to pick her up...to make sure that she is home and she is fed...so during that period of time was quite challenging...that's also part of the reason why I switched job lah...ya</p> <p>May: For me I'm a university grad which means... I was working for 20 years... I did work and I do have some CPF I do have some capabilities lah I won't say I don't have a choice but I made a choice you know I made a decision that I will leave my career and change you know...adjust my erm schedule take a part-time job you know to manage both...although I'm a single parent...that's why is tough because single parent means no choice. Must work. Cannot work full time lah but I have come to the stage where I really have to think about my finances...?</p> <p>Ashley: Last time is because when I have second child, I on shift work so afterwards when I have depression so I resigned I switched to office hour so is better already. Ya because if shiftwork I will be on afternoon shift by the time I come back the children sleep already</p> <p>Amber: Currently now I am not a teacher I am working in MSF actually. So I'm actually a quality assessor in preschool which I think is also good lah because as a teacher, I would not have much time to work with my boy. Ya because a teacher's work is 24, is very close to 24hours.</p>
	Managing caregiver role and spousal relationship status	Support from spouse	<p>Maple: okay when you have a special need kid...some spouse arh husband and wife...some really give you support and take care of the children...some is the husband can accept wife cannot accept ...some is wife can accept husband cannot husband...some cannot then they divorce...some is they cannot accept they run away then they throw to ahma...we also got get such cases...a lot of these type of issue...some is parents cannot take care throw to home no choice lah throw to home...then some is like they got 3 4 children only this one has problem...very sad de leh..actually initially I cannot take it now I</p>

		<p>okay already you hear already very sad...because those problematic one the parent don't want take care they take care the normal...or some of them is no choice their focus is more on normal kid then the special need kid neglect...or some of them is the other way round they really too much on special needs kid they neglect the normal one then the normal one also got issue because they find the parent also never give them the kind of attention they always focus then they will keep telling the normal kid you must take care of the special kid...so eventually there is a lot of problem...now everybody sharing lah</p> <p>Jane: No in the beginning is very difficult to cope this situation like this then the father also angry show temper so we become 2 persons. After I come back from work and she show me the father beat her she sit one side so I took her down to see doctor to get evidence and then someday again like that no choice lah we have to bring her see the IMH tell her stay in the hospital.</p> <p>Elise: my husband and I we are the only one taking care of her out of the school hour...eh out of the work hours...because uhm we our parents stay quite far away so they can't really help us...then in the past we used to send her to a nanny...</p> <p>Tom: Yes because 2 of us agreed mah. We agreed that because you see, from 7 plus to about 12 plus she is in school. She is in school trying to focus and absorb whatever is being taught in school. So reach home, I don't think I want her to go through that again that process. So is time to relax what (loud) you get what I mean? So let her relax until my wife come back after dinner everything</p>
	Managing caregiver role and spousal relationship status	<p>Sandra: Actually, I know of so many things arh, then my husband sometimes he say he is tired he doesn't help me. He is supposed to teach him chines when he was young. I say I teach hi English. Is peak to you in English you speak to him in Chinese today my boy he don't know a word of Chinese only know one two three and that is being taught during tour take photo one two three...then he say one two tree. Now is bye, morning these few word only and is not taught by</p>

			<p>my husband. I so angry I say baby that time I speak English, you speak mandarin. I cannot be doing everything. I train from rolling him going up and down everything is me until the boy don't like me</p> <p>Jane: so I just tell him we don't quarrel at home in front of her...maybe that is the reason...when she hear we quarrel then her behavior change...that's what I think luh from what I gather so I just keep to myself...</p> <p>Krystal: But I'm not really in the same page because he is so experience and so knowledgeable about this area, sometimes he nag a lot of me on what I should do. So I'm very stressed sometimes when after work he will say like cannot let him watch the tv for so long so I always limit him like 1 hour then after that he will ask me to play with him certain games aiya very stressed.</p>
	Impact of role overload	Intrapsychic strain: Incongruence between desires and current state of life	<p>Pamela: Throughout my life I think is erm, I don't have a life of my own for the last ...because that time my second son was in p5 and my eldest son was in sec 1 so I don't have a life of my own because of these 3 children and secondly is that my husband, he has to work overseas because I stop working. So he told me to just focus on our child but he has to take the job that he has to be stationed overseas. So, I'm with the children all the time</p> <p>Pamela: right now she is a teenager is a bit difficult in a way that her way of thinking is different but when there is time of let's say, disobedience that kind of thing, I would reason out with her and ask her say that did you know (pauses) erm what your mother has to go through in order that you can achieve what you have right now, right? And I said that to me, I will not compromise on disobedience. I told her that you know, if you don't need my help right, I can always go back to the workforce and I said is easier for me to employ a maid, okay I just pay the maid, I don't have to care what happens at home. That means, your development all that, I don't have to bother. Whether you do right you do wrong right, I don't see so it doesn't affect me. But the thing I said that, why your daddy has to go overseas</p>

			<p>to work. Why do I have to stop working? I said if I go and work right, I have my own life you know. You know, I just go out and work, in the end I see you hi hi bye bye and go and sleep. but why do I have to sit here, watch you and correct you. Is aid the most difficult thing is to correct a person.</p> <p>May: Then I start to move on with my career or take some cleaning that I want to do...so I just need to give him a bit more time</p> <p>Jamie: initially I was like thinking to work full time then my mum will take care of him but everything change so erm... initially I was like very angry lah like how come you can't handle you know then you want me to resign all that...but after like probably 2 months arh...ya around 2 months later as in like I can see slight improving in him...so thinking of it like maybe is worth...that's why until now lorh</p>
	Managing role overload	Informal family social support	<p>Sanders: I feel like I was given a death sentence at some point, I thought really nobody care including my own family...most of my family they don't really help with my son they don't know him except my mother. So in many ways, this is a very difficult situation and something needs to be changed.</p> <p>Pang: At that time ya my daughter has not gone to school yet...so the maid will sometimes like headache lorh...the 2 of them will just...the maid will just do cleaning then the 2 of them in the room. I don't know play Lego and make noise...then the maid will come and scold my son...</p> <p>Kate: No lah but they all...I've also got...as I say luh actually family support is very important. Because when I have the 3...4 of them... my mother in law was still around and she was staying with me so she's helping me to look after together with my maid as well. So that's why lorh I say family support is most important.</p>
	Managing role overload	Downward social comparison between individual with NDD	<p>Pang: so he was very impressed that nick you know like the guy with no arms no legs can do so many things and the more you can do it because you know you are abled you have abled body you can do so many things ya...</p>

		and other disability condition	<p>Victoria: so at least I'm physically aware ler I would say compare to other special need kids when they are not verbal enough so they will have a lot of problem and when you are not expressive enough as well... you tend not to you know understand. how should I say...understand his emotional and things like that.mine was easier case I don't really have to erm prompt him don't do bad things lah because from young you know I've already do a checklist with him so he knows what time he needs to get up, what time he needs to shower, what time he needs to get to school, so he's already very monitored at a very young age.</p> <p>Penny: ya ya we punish him also you know...some parents they give way a lot no no you cannot give way because down syndrome is different from autistic down syndrome can be taught but you must have love and patience see...</p> <p>Sandra: As I say the child grow up he is very adorable. One thing he is very adorable I can tell you. Downs kid are very adorable. He doesn't give me that kind of emotional, not say emotional. I mean he doesn't give problem like some of the autistic children screaming arh...down syndrome okay one, they are very guai...slow learner but on the whole very guai.</p> <p>Ashley: Because ADHD they are still, their IQ is still quite good one so they can still function in mainstream lorh except for those what is it called...the GDD they are slower so maybe they are not able to catch up maybe they can put them in another class where the pace is slower</p> <p>Maple: Ya even sometimes you must think lah...I'm quite fortunate that my son[diagnosed with ASD] is not serious because like watch a movie only eh their kids also cannot eh I have parents share with me arh they kena kick out by the movie theatre</p> <p>Krystal: Ya where they[autistic children] would just hit people or bang so as compared to them I think I'm lucky I mean [son name] is quite okay...he doesn't have this kind of very erratic behavior and ya</p>
--	--	--------------------------------	---

			<p>Elise: Ya is troublesome definitely...but even bringing my girl to rainbow center right now right I feel that...okay because for her like I mention I feel that she is quite mild...but when she is being put in the group...of course they already try their best to group people of similar ability together ...but in that class mix right she is considered one of the better one luh I feel...there is also 1 pair of twin who is similar to her...but for the other three right...because for rainbow center they take in a mix of different developmental delay luh...so I think in the class</p> <p>Pamela: I don't think its that severe because I know that some ADHD has problems you know erm... how do you say...making friends...like the social cues all that they couldn't really get it...but he seems to be okay...so that part I'm grateful luh..</p> <p>Pang: So, maybe sometimes I feel it that, (pauses) you know the way I talk to her that's why she is mature in her age because from young all that. That's why when she went to p1 all that, her peers are different you see, different from her...because the way she speaks is more mature then they cannot relate to her or she cannot.</p> <p>Penny: all down syndrome love eating you know so must watch their diet...they don't know arh..but brandon is very good looking you know most of them are very fat</p> <p>Tom: She doesn't hold grudges. You know is not like other kids they hold. She doesn't (emphasizes) she just get angry for a while after that just dissipates so she is very loving she loves hug she love to do this ...and she is very nice you know (emphasizes) .</p>
	Managing role overload	Personal time as coping mechanism	<p>Jamie: de-stress moment very important</p> <p>Cheryl: Time for myself quite hard sometimes when I finish on someday I have time for myself I will eat my lunch quietly and relax...ya its small time like this</p> <p>Maple: Yes and you yourself also can relax mah you send your kids 7 something and school they really provide a lot of support even the school bus you send your kid 7 plus to school the kid 1 plus come</p>

			<p>back during this period of time isn't it your relieve time until they come back then you start your routine again right</p> <p>Sanders: So actually the fundamental, ya actually this reminds me of psychologist said that people don't realize that this is part and parcel of being a carer is this connection with what you call your inner child. who is your inner child, the person that have always...you have forgotten actually as an adult, when you started to work, like what do you really love doing like just do coloring. You like go and do it , you know just and be silly thing that you like go dancing, listening to music . I went on a trip recently and was street performers and it was so fun on Paris and there are just wow incredible music, I went to bookstore and I realize how much I love introspective memorial that is written in poetic prose...I remember you know because ya...so</p> <p>Amber: So, we try to factor in some time. Then I also have, very Monday is my personal time. I declare to my husband. I say okay I think I need my personal time, so every Monday is my personal time so is for me to go shopping go facial go do hair, do nail do all the lady thing. So, I declare one, self-declare he say okay. So, I say Monday you must stay home and work with the big boy for his enrichment.</p> <p>Sandra: Ya own free time. When my son is in school, I do my own thing lah. Must keep myself occupied or else can go crazy one</p>
Theme 4: Me and my child with NDD: Interaction with individual with NDD in Singapore	Interaction as an Educator	Academic-oriented	<p>Elise: For me as of now , I feel that for my girl's case right...I personally feel that she is probably not a very severe case...so for now my intention is to send her to a mainstream school...but of course she is very young so I cant say for sure....but I've been quite hopeful since her speech has started...so far I feel that is still pretty possible for her to go mainstream school...so I cannot really consider too much about that now luh...right now for us is just to make sure that she has enough stimulation she is going for her early intervention class</p> <p>Amber: So fortunately, I think thank god, my son like letters a lot A-Z the alphabet, so she actually leverages on that and she get him to learn</p>

			<p>spelling and then now we are learning comprehension like we will...so spelling is like letter to letter matching and then comprehension is like guiding him like what is this boy doing so she is kind of broadening it lah. Like now she is teaching us how to teach him categories of things so is really day to day that we will ask him okay name me 5 types of transport...then he will say bus, car...so we expose him through word cards and also pictures</p> <p>Tom: Ya lah so , I think she still needs to learn a lot of things like because her school is Tanglin school is academic also she I really need to push her to study</p> <p>Ashley: my interaction with her arh sometimes have to be firm lorh because if she doesn't want to do especially maths arh she her worst subject is math so if she reluctant to do then I will tell if she don't do then Saturday don't come for Zumba. Ya is something like a consequence. I say is a reward if you do all your homework then I bring you for Zumba.</p> <p>Victoria: So I explain to him that identity is very important is your belonging so I tell him he needs to be kept proud of his own name in that sense I told him learn how to write..so I gave him a lot of playdough I form a lot of letters make him follow at a very young age..so eventually you know as he grows up he tend to take a pencil and say ya I'm going to write my own name</p>
	Criticism	Internal attribution to child	<p>Valerie: You know, I'm sure you will find most of the parents you feel sorry for their kids because the kids are just getting into trouble all the time and they are just used to this, so called just getting into trouble, they get their reputation in school, mix with certain naughty kids and they get blame for certain things. not Michael, he did get into trouble and it was his fault.</p> <p>Candy: she needs to organize things by herself but still in quite early stages which cannot allow her to organize everything fully and then somehow her development of understanding the environment or something the other things the people's mind , reading people's mind,</p>

			<p>I think it is quite behind so to talk to her reasons erm doesn't mean anything, useless so it is quite frustrating .</p> <p>Maple: Ya but is very frustrating for us luh because the whole family gets affected by his crying everything because he got 2 elder sister which is like teenager, so they have to go school secondary school so is the whole family...imagine he can cry in the middle of the night 3 4 am he also can start to make nosie so whole family cannot sleep well lorh</p> <p>Sanders: We call it second class treatment of special needs people. These has very much carved their mentality and when you live under this kind of shadow. You start start to development I would call a bit of the inferior complex in many ways because of how bad this is like. They blame their kids. If you are born normal right, then you will be getting first class treatment like everybody else and I wouldn't be paying these very heavy fees but you know, bad luck. Is not the government is bad. Is because you born like this and now we don't get to get the treatment that everybody get.</p>
	Criticism	Pervasiveness of implicit prejudice	<p>Sanders: They were all like fighting to who wants to take Sebastian because he was a novel for them because he is mix blood you know. Very interesting for them plus his odd mannerism right so we try to explain to him that you know...and is very hard to explain to them...we always go like something like that this is what we learn in Thailand like he is crazy so simple gesture and then they like they are cool and so yes...</p> <p>Anne: Yes yes yes ...and then we occasionally bring him out because it is a little troublesome to bring him out because he is autistic so sometimes he will own self run around non-stop and he cannot control his own temper.</p> <p>Cheryl: Ya so is.. I also couldn't understand so they didn't interact with my child although with weird behaviour luh...actually wouldn't call it weird is just the way of that... excited lots of energy so they don't approach them.</p>

			<p>Pamela: And then I told her I'm sorry just now you know when I was teaching you but I said, if is too difficult, there is always another school for you, you know. People who are like you, you can take your time to learn, you will be happy, you know there is not so much on not academic you know.</p> <p>Sandra: Put my son there I think my son will feel why all the small ones here but he doesn't know his brain is even lower than some of this kindergarten people. Eh nowadays kindergarten can speak so well and read thick thick books</p> <p>May: I didn't know my child was going to be like that that useless kind of feeling....</p> <p>Valerie: But occasionally, all the kids will be being stupid in the class because he is the one, the ADHD kid is the one who doesn't read when the situation changes so all of a sudden, there is teachers coming through the door and all the other kids get that, they stop and your child is still being stupid and there are the ones who get into trouble so it's tricky.</p> <p>Sanders: They didn't know that because we were very used to traumatizing their kids ...very used to them looking but we can step back then you see...oh please don't do that. You wouldn't do that to a normal person but we are so used to them acting strangely and being difficult that we don't even realize when they are hyperventilating nothing nobody cares. That's the scary part not because they don't care but they are kind of used to it.</p> <p>Candy: Basically you know ADHD kids are very impulsive and short-tempered and that they are ...they tell a lot of a bad things even towards teachers, supervisors or even for parents. They are very slow to do something because their attention cannot stay still so even now that she is P3 8 years old and going to be 9 years old, she cannot flush the toilet every time.</p>
--	--	--	---

	Criticism	Upward Social comparison between individual with NDD and sibling	<p>Pang: It's very different when I deal with my daughter...ya its very different you know because with my daughter you know she is the type that she wants to do thing...it's the total opposite.[...]for me I have to chase my son and lie</p> <p>Valerie: Erm he's a second child and erm I told a lot of differences was because of the gender.so my daughter, who is adopted, is always very compliant. Erm she would sleep, she slept through the night at 6 weeks old and in a playgroup situation, I wouldn't be on the floor because I'm not that kind of mother. Like a playgroup, she'll going to be playing along with the kids and I'll be chat chat chat...and I saw her at 6 months old she was crawling towards something and I just went (coughing sound), and she stopped, look back and she just reverses now she is like that, she is naturally (emphasizes) a compliant child, person. He was, then he came along (laughter), like oh god</p> <p>Cheryl: The elder boy is so different he is very talkative sometimes he will bring book and sit close to me .With the younger child, things take on a different dynamic... like things you used to take for granted like eating out and uhm doing simple things become much more ..you need more time or you just don't do it anymore...ya</p> <p>Pamela: Because the brother is very good at math, so he just walk past only, he says check your work, you know there is error all that. Then for her, she is very erm defensive arh. Why you always say, why you say wrong that kind of thing. Then after that when I heard such things, I come out and say look, if your brother tells you wrong, you better go and check because he is very fast. The minute he sees, he knows whether is right or wrong. I say if you cannot accept it, then just prepared to get it wrong.</p>
--	-----------	--	--

	Criticism	Upward Social comparison individual with NDD and other typical children	<p>Krystal: actually because he hasn't been learning I mean he hasn't been about to speak quite a number of word as compared to his peer of the same age sometimes I find myself talking just have to keep on talking but is like nobody answer but because he's absorbing you know ya</p> <p>Anne: Ya they are still stuck in their own mind-set...why is it that my child can do such things but your child cannot do such things...and some will feel that...you try using typical way to bring up your child...of course we want to right but the problem is that he cannot...I also understand and wish to wish the normal of upbringing a child...like I use typical way of teaching a child to special needs but he cannot absorb...</p> <p>Cheryl: Ya it's more of that most people have kids because they are so lovely right they can play with you or say some kind of remark that eh you don't expect them to say at this age that makes you feel so...like woah the wonder of my child right..ya so all these is very different from a normal and special need kid.</p> <p>Sandra: People 2 years already running around, talking. Mine arh, still walking up and down the stairs and then my boy only start talking at erm 8 years old then call me mummy.</p>
	Emotional over-involvement	Protective of individual with NDD-Excessive worry about survival in Singapore	<p>Victoria: okay I have actually instilled something in my son is he will not always be alone even though I'm not with him you know just like a button from his mobile he is able to trace me... so that give him a security and he knows the mummy will always be there for him and that is also something a lot of special needs student are lacking...they got no security from the parents</p> <p>Pamela: They always check all her files so when go for her PSLE. I put her on foundation. The teacher wanted her to do standard. I said no, I said that for the other children, they are already so stressed. I said I do not want her to go through.</p> <p>Sandra: Singapore schools are different you know, not like other country arh they integrate from very young...ours is somehow arh,</p>

			<p>maybe because the school syllabus is so difficult, the normal children already some of them cannot cope all the more our downs kid.</p> <p>Ashley: But the first week I train er the second week I actually become a private PI I follow behind shadow her arh got people who want to erm stranger want to to ladies usually ladies not guys lah strangers at 6th avenue there they want to go home with her. The auntie actually want her Chinese lady maybe they are lonely want to go home with her. You want to go home with me I cook for you...my daughter say no im staying at ____ I cannot talk to stranger...okay I was behind lah so I hear the conversation</p> <p>Jamie: Because they take longer to learn and adapt to the area compared to normal child...so ya lorh we also have to think of the child whether he's okay during...erm...to merge them together...or so may be bullied by them...I don't know</p> <p>Elise: ... honestly I think maybe not all parents will be receptive because like I mentioned...you know there is still a stigma there...like you know when you send your kid to early intervention center does it mean that she is...would people look at her in a different light...</p>
	Emotional over-involvement	Protective of individual with NDD -Excessive worry about future	<p>Penny: but keep on pushing on...like they like dancing lorh all these things...aiya very sad lah I see them having a child like that is very very sad...every parent say let him go first which is not say wicked luh if you go first you don't know what will happen to them...even though you got money you put them in a home is totally different now they have this deputyship all these...very different lah very very difficult to say lah...</p> <p>Sandra: Is who take care of him that is my main concern. Who takes care of him later on. Whether they know how to mange him or what or send him to a home. I don't want him to be a home. That is our concern. In fact all the parent our concern is when we are around we can take care of them because some parents keep the children at home. mine already so mild is till have to think of future where to let him stay.</p>

			<p>Ashley: Have to put aside some money for her. A trust fund for her. In case both of us are not around at least the brother will not feel burdened</p> <p>Pamela: That's why I say for me if the child gets bullied, I say better they get bullied now when I am still around and I can teach them and tell them how to move on.</p> <p>Krystal: Maybe I teach him because I also hope that when he grows older he gets independence so that next time when he is like 14 15 years old at least he dares to go out alone right</p> <p>Amber: Okay lah hopes for myself don't have lah but basically of him is erm to be independent and then he is able to gainfully employed for his own survival and to have meaning in his life lah, that's more important. And another element for me because I'm a Christian, I hope he will be able to find God. No broad dreams lah, really up to his interest.</p> <p>Kate: To her to be self-sufficient to be able to live on her own if she can. I mean this is what I think most of the parents fear. What happens if I grow old when I'm gone whose going to take care of her?</p> <p>Tom: so long she know what is right what is wrong, she is able to read she is able to do whatever, travel or independently that is more important. Then erm, ultimately, whether is she able to be gainfully employed, alright, to lead an independent live and earn her own income, we also worried about that</p> <p>Jamie: So little improvement from him is really happy moment for us already...I can't think of the future but I will only think of now or the next day that kind ya... as long as he is not in danger that kind of for now luh...</p> <p>Cheryl: Just hope in future our country don't know... build a place for them where they can live together</p>
	Emotional over-involvement	Self-sacrifice	<p>Jane: so I also volunteer help do the work then take volunteer help them do the beads sorting out the beads...so many fine fine ones so many bowls so I help her sort it out and make her do...for about 3</p>

			<p>months I do that because at that time I quit my job already to help her out...</p> <p>Cheryl: this is what have been told to me to like build up his awareness. I can't just leave education for these few hour so everyday become something to do meaningful activity</p> <p>May: Initially, I mean for the past years when he is schooling, I always bring him to down syndrome association for his enrichment classes...erm I tried to increase you know like almost every day he will have some form of enrichment and then he has outing then later on he has got performances....so every day is like an adventure every day is very exciting I think. Initially it was very tiring for him but then later I started to supplement his food with vitamins.[...]My parent my sister say why are you doing this why are you so they say kiasu I say no yes I am kiasu for him because I want him to learn...</p>
	Emotional over-involvement	Controlling child's behaviour	<p>Pang: ...for example he was working on piano...make him do piano...because I see the benefit in it you know...not long only 5 to 10 minutes everyday and sometimes he get very fed up because you know he make mistake, then get very frustrated so difficult...I'm was like no you got to do it..i also have a like some reward chart..</p> <p>Penny: he attended a lot of seminar people from overseas they come in a lot luh...I will try my best to push him so I find him very good.[...]he even model for top men clothes a short while only luh...I push him a lot luh so they dress him then they would teach him a catwalk then after that he knows how to pose...I was thinking if I get some ...I mean some modelling thing at least for graceful and reward, they cannot they say no luh some parents I don't think they will like</p> <p>Jane: after that I found a disabled lady she's selling a lot of charity goods so I approach her many times then the girl finally give me one paper, friends of disabled. So I called up the lady help them ask me to bring her down for interview. She's willing to accept her to work</p> <p>Victoria: Yes I expose him and all the activities I made him or join him in or let him go, he's mixing with people from normal schools,</p>

			mainstream schools. He's hanging out with a lot of adult and normal kids.so in terms of confidence it's very high
	Outcome of expressed emotions	Impact on dyadic interaction between caregiver and child with NDD.	<p>Sanders: You know, actually by the young man stage, they are very sensitive. It boils down to love because at this point, it becomes very love. They are not getting love anywhere else in any significant way. There is no girlfriend especially for my son. There are people but he has to get it from his parents.</p> <p>Penny: for me I will feel is this way but now they treat them like gold wah they will give them birthday party those rich one so different they really enjoy life so it's totally different because a lot of love is given to them now plenty of things are given to them medical...special needs you think what all these...all these people who join the down syndrome association mostly can afford...so they give the best treatment so that's why they can live longer...</p> <p>Pang: ya so it depends on erm how the parents actually see the child if the child see that...if the parent see the child as hopeless, then maybe he will...then it will reflect as well on him that you feel that...oh my parents actually think that I'm hopeless you know...but then if you actually if encouraging them and you see them differently...then you know then the child can feel it as well...oh my parents love me the way I am ...ya so it really depends.</p> <p>Valerie: I think is very hard because when we did a study with our members and other people about discrimination in the workplace, is not just the workplace or trying to get into the workplace but is the whole, the pre-employment stage, including their upbringing their family, and some of the worst discrimination is from their family. It was heart-breaking you know. People say they are no good, good for nothing,</p> <p>Pamela: He wrote words you know, big whiteboard, he wrote down my ex-husband who hated him. He wrote his name, big like just one-word whiteboard just his name. oh boy, I thought it was nothing ...it</p>

			<p>happens when he was 12 but when the explosion came at 15 plus he wrote his names...amidst all the words he wrote about his entire life...is all ang mo kio mrt, nai nai house, all kind of things.... all these stuff that I was like oh my god he was sharing, registering life...then at the back ground I see, my ex-husband name stretching from the top of the whiteboard to bottom. This is communication the size of the lettering tells me like you owe me big for this one. He was really not a nice man. You kept him in my life for 10 years. I owe this against you. You know, communication. And then for me was like okay I understand but what should I do about it. What should I do about that?</p> <p>Pamela: if some parents are ignorant lah and then if they shelter, they do not even want to go and embrace or learn what is special needs and that's when they give the fear to their own children they say don't go near is contagious that kind of thing then of course it will spread, it will go down.</p> <p>Sanders: If they say I am not embarrassed about this, no big deal right but how about if my son is jerky of with his penis the whole time or doing something weird or going round removing sticker or anything. I mean this is a bit tougher to deal with...or starts yelling and screaming or jump up in the air screaming...I am giving you all these example that my son did in public. So is that something that parents can accept? Is that something they are not going to feel weird about in public? So the interaction of all those factor right affect how the parent can feel. So regardless of whether the society wants to stigmatize them or not , sometimes this is also the issue so there is interaction between parent and kids right, but of course with the dynamic flow right although, the stressor the perception is all lead on each other. So the kids are also feeling how far the people are afraid of them then they act out some more but they themselves can also be afraid because some sensory stimulus that maybe has nothing with the public is feeling but they are acting out in this way then the public or</p>
--	--	--	---

			parent are horrified of them then it get worse then there are some many factors that is going on even within the autistic person that is independent of the parent and the public. So this is what makes it so complex.
Theme 5: “Navigating me and my child in Singapore”	Attitude and behaviour towards individuals with NDD in Singapore	Presence of implicit prejudice attitude	<p>Pang: I mean personally I think is okay but erm for other parents, I don’t know erm...because sometime I read in the paper...if the kids behave like you know...erm they throw tantrums for example...the parents will criticize like erm how come you never teach ...ya I attended this ADHD seminar before there are a lot of feedback from the parents so the parents were sharing with us how that ...you know...the kids were being ostracized as in like you know because he behave differently you know...he will do like all these things that are not socially acceptable you know..and erm ya then the parents will like tell the kids don’t make friends with him..or in public when the kid throw tantrum and then everyone will be like how come you never educate your child you know...</p> <p>Valerie: Erm , I think there are some very enlightened people in this country, I think there is still some people who really are not sure about polite way of putting it really but they need to have their eyes open and they need to think a little bit more.</p> <p>Valerie But I have a lot of difficulty here is that as I’ve mentioned about education here, a lot of people in Singapore do not grow up alongside with kids with disability. So when they do see, of course with enabling village and you got the inclusive kindergarten, that’s great but its pipeline thing so once people start growing up with a diverse population. Once people with disabilities are educated so they are the in the pipeline for the workforce, things will change. It’s a very slow process</p> <p>Victoria: Asian ideology is one thing. but I think Singaporeans on the hold they judge the surrounding you know and the environment with their own thoughts. They don’t judge a special child or a special need</p>

			<p>child from the thought of another party. They just jump to the conclusion and say look at the child...</p> <p>Maple: maybe let them know that all these kids are not sick patients (bu shi you bing de ren lah) lah...because I know their behavior issue can be scary sometime I see the way they behave also scary but then majority are harmless...</p>
	Attitude and behaviour towards individuals with NDD in Singapore	Lack knowledge and empathy	<p>Cheryl: What I need is the understanding like okay that this child need more child to calm down or this child need the experience to understand the world works and the bus stop even without all these experience mostly in public area they cannot learn anything</p> <p>Tom: I think also maybe erm before that he was also bringing her take MRT I think he has observed a lot. Students from her school is not only compromising Down syndrome also a lot of ASD. Some of them erm they are in a world of their own. They will scream, they will laugh, then they will you get what I mean. So people on board MRT busses will start at them looking at them like they are an alien you know some of them agitated but come-on when you take a look at them, you know that they are special, so can't you just be more humble, give some more consideration, you get what I mean.</p> <p>Elise: I think is really hard honestly for erm a set of parents or even non parents to understand or to even erm...really think like an inclusive society...I feel like I mean because they did not go through the thing that you know special need kids parents or special needs kids went through so they wouldn't be able to understand like erm...the kind of what how do I put it arh...they wouldn't be able to understand that kind of erm challenges that they go through and maybe maybe you know like for a lot autistic kids....they actually can display some behaviour in public...</p> <p>Anne: I think it is very difficult not so easy I feel. Because it is not easy...actually it is not that it is not easy but sometimes, people don't understand, don't understand that this kid has problems they think that the parents did not educate the child well ...it is impossible that a</p>

			<p>child is like that must be the parents never provide proper upbringing for the kid...</p> <p>Pamela: So the thing is in order to embrace special needs all that, they have to know lah. How I wish the education is that they can add in something whereby here is a special need portion where not all child are typical, some are born different and then the acceptance ah veto be there and treat everyone with respect because they are also an individual, a human being.</p> <p>Elise: ... honestly I think maybe not all parents will be receptive because like I mentioned...you know there is still a stigma there...like you know when you send your kid to early intervention center does it mean that she is...would people look at her in a different light...</p>
	Attitude and behaviour towards individuals with NDD in Singapore	Discrimination	<p>Sandra: They don't call him uncle because he is special need. Some of them just ignore him and the younger generation supposed to call him uncle you know. Some don't bother just call him by his name Samuel. Don't bother to call him uncle even though he is uncle in that the parent generation so like that loh. So cannot fit in with them.</p> <p>Penny: they are afraid of parents...its true when he was in school go swimming the minute this batch go in I can see all call the children the come out...is really true...of course now open up a lot open up is the parents they accept the children they treat the kid as bao (precious in Chinese) very good but not outside I think there is still a long way to go</p> <p>Cheryl: most people shy away from people behaving strange... straight away your mentality is you're weird don't go near him later he hurt me you know people here have this fear don't disturb all of us mind our own business right yeah so yes</p> <p>Sandra: No when he was young I bring him ok he can mix but at that time the schools don't accept. Even kindergarten say we don't take in downs, so I got problem sending him to school. That time already marginalized in a sense that they just tell them sorry we don't want other children to leave because of you son. I was told once like that</p>

			you know. one catholic school, kindergarten I put my son there half a day only. The principle told me sorry I don't want the other parents to leave because of your boy
	Cultural values and norms in Singapore	Kiasu mentality	<p>Penny: it's okay because she has to accept sometimes in developing stages but already started and she needs to overcome and she needs to adjust herself to the society with a lot of "kiasu" friends right (laughter).</p> <p>Candy: Society wise, erm it is very good for the ADHD kids and then for other kids that you are now studying. But the problem is the parents, the "kiasu" parents. They always think about their children first so they complain a lot about our daughter so we suffer and then she also suffered right she was kick out two (emphasis) or maybe three times (sheepish laugh). Ya because of the complains from the parents.</p>
	Cultural values and norms in Singapore	Pragmatic society that values academic competence	<p>Amber: But I think, I can understand the government point of view. They don't want these children to be left behind right because of the simple fact that we are a meritocratic society and they are still going for the inclusive society.</p> <p>Krystal I think is difficult because firstly we are in a very competitive society hard to say is not really the government fault lah is the parents everybody right. Even normal kids we already compete...</p> <p>Sanders: I do agree that a lot of parents are still trapped very much in their conventional mindset is because of how they are brought up in Singapore and they were meant to have normal kids. They are very ill equipped especially to handle special need kids but having said that, most people regardless of which part of the world they hare in , have a hard time with autistic kid, very hard time is not easy in any country. But when you of this society that celebrates and rewards mainstream norms, then it is especially difficult...so I think that don't be so hard on parents...they are parents, Singaporeans and I used to be very impatient about them but I understand where they come from. They</p>

			<p>drive me crazy trust me it has been frustrating honestly, I feel very alone.</p> <p>Victoria: Because guess what, we live in this world so we talk about normalizing somebody...we are talking about equipping them in the best way to function in this society.</p> <p>Candy: In Singapore, many kids is supposed to do just study study study all the time right? And then some things like keeping the room and cleaning the rooms, laundry their clothing, thing the very kind of lower level of the work so I met a lady, old lady on the street at that time I was scolding her, my daughter and then she said. Because she lied about study homework, she said that she didn't need to do a homework and then it was a lie. And then I scold about this on the street because like I don't bad to scold my daughter in public is not a shame. And then an old lady came to us and then she was listening to our story and she say ooh if you don't study you will become a cleaner or something. That kind of thinking ways are all very common here right. And even in hawker centers, to say thank you to cleaner, to keep trays by ourselves, very natural for me but not Singaporeans. So I think in a kind of society must be changed..</p>
	Helplessness in relation to formal social support	Lack of support/knowledge avenue for caregivers	<p>Cheryl: Improvements arh...improvements I would see not much more for wheelchair bound people with the blue logo right other thing not really. There isn't much message to promote inclusion or to tell people how does an autism kid really look like and what do you do</p> <p>Sandra: Not enough support. No social team. A lot of thing we need to have self-support. Not enough self-support team. Everybody individual have to help themselves</p> <p>Maple: The parents need a lot of support also because is not easy arh as I say...sad to say some of them come from broken families some of them don't have financial support some of them just throw them at home lorh...some of them just throw at home lorh they don't know how to handle</p>

			<p>Victoria: Second thing. I've met parents who come from a very normal family. Okay the only daddy who is the breadwinner of the family but they got no knowledge but they are very supportive of the child ...but the child is not given that different choice and that is also another one more aspect in a way that they don't have enough support be it from the school or even be it from the hospital because there are too many strings attached.</p> <p>Amber: Nothing and you cannot expect that every special needs family is like my family you know where I can provide, I can have the knowledge I know how to handle. There are some families they don't have the financial means, and maybe the parents are also not very educated. They are clueless about what to do, then how are we going to reach out to these. I think they are not doing enough.</p> <p>Tom: ya first point of contact, so maybe hospitals the social worker, whether is private or for public hospitals lah, maybe they should come up with something where if they know that the baby is , is born with some special needs, they should actually already talk to the parents say eh there is such organizations that you can seek help that kind of stuff. After that arh, the knowledge is already passed to the parents, is whether the parents know about the avenue where to go. And maybe they can tell them, eh there is such a support group that kind why not?</p>
	Helplessness in relation to formal social support	Insufficient trained professionals	<p>Suzy: support not there yet even in healthcare, medical profession not trained in this area, don't really know how to mange</p> <p>Victoria: Ya even in hospital it's totally different. When you take a look at hospital in general a child specialist in general a child specialist who handle special need there are not a plenty but there are many doctors who can handle normal children but there are not many doctor who can handle special needs</p> <p>Sandra: And then went to APSN they give him therapy keep changing every year one ang moh, one form sri lanka, one form india, you know the accent arh...the accent is different you know...then our children already special need what they cannot understand. By the</p>

			<p>time they manage to listen to the accent and learn, the fellow resign. I tell you, they keep changing therapist. Speech therapist especially i think speech therapist cannot survive in school too tiring. I go outside I charge so high. In special needs school, how much do I earn and throughout the day I got student in fornt of me that need to talk. Not the fellow talking but you leh all special needs one leh...so the poor therapist...half a year last the long resign. Then another one, come in from poor country...accent. Indian eh sri lanka coming in talk talk talk ang moh also got lah but don't know what they speak...even I talk to them I got to listen for their accent. So like that, how to learn</p> <p>Ashley: Uhm. I feel that the school probably only have 1 social worker, if I'm not wrong is social worker and 1 psychologist and 1 occupation therapist only. One one one. So to cater for the whole school, I think they only focus on those that really need</p> <p>Maple: Because they [PCF] cannot handle him. They keep telling me they only got 2 teachers for the whole class then my son was like during that time he never go for OT ST mah so he; s running about run and run so he cannot concentrate and the teacher could not handle because teacher not special need train...</p> <p>Valerie: Try to get the school alongside you, try to get their support and if you don't get their support fight them. I know that it is difficult, I know it is difficult, I know resources are strained.</p> <p>Amber: That's why pathlight is to me is very good. Because the class size is small, they have like probably 10 or 12 children they have 2 teachers there then the teachers are trained so they know how to do the work schedule and then they have, every classroom they have a room. They call it a...I don't know what room lah.is basically for the child to go in and clam himself down. The calm down room or something like that. So therefore, is something like one child is disruptive at least the child got a place to go to, to cool, then the rest of the class is not</p>
--	--	--	---

			<p>disrupted what. But the mainstream doesn't have this setting and teachers are not trained.</p> <p>Tom: Then of course the support from the teachers are very important because I don't blame them. Not all teachers are equipped with that kind of knowledge to handle such children. But let's say NIE is able to guide them and teaches them eh this is how you handle such children, then at least the teachers are more confident in handling</p> <p>Sanders: I felt it later...like being hold in a hostage situation...you going to blow it if you really antagonize the teacher then the kid will get thrown out then you have to work, you have to pay...you don't want your kid to get kick out...so whatever teacher is right or else I also heard erm principals hiding what happen, teachers lying...pretending nothing bad happened... I used to scare... get phone call from parent in the middle of the night sometimes telling me what happen about bruises on their kids and then learning that their kid have been bullied an teacher knew about it didn't tell pretending they don't know because will look bad on them.</p>
	Helplessness in relation to formal social support	Long waiting time for resources	<p>Maple: but while waiting for diagnosis arh from child developmental doctor to go for EPIC luh...that time I choose EPIC...the waiting time mah you know right the appointment you cannot get it...so during that time is really worst lorh.</p> <p>Elise: Ya the waiting time is very long...I think we seen the doctor first time in maybe end April last year...ya so she only mange to ...there was a speech therapy like for teaching session for caregivers lah..But it happen sometime in...I can't remember exactly when but maybe July or maybe June I can't remember ya and then the first speech therapy session only started in September...</p> <p>Anne: Waiting time arh...time arh...kk will wait very long in term of waiting list...</p> <p>Amber: Honestly, I think in terms of giving the provision for children with special need is insufficient in Singapore that's for sure. You</p>

			<p>know like when we want to apply for early intervention centres and the queue is so long. For my boy case, I need to wait for a year. So, number one, that's not enough. So, in terms of placement, special school is not enough.</p> <p>Cheryl: Erm no I personally don't think so. resources are there but it is not available to you immediately. Firstly the appointment at KKH take a while to go and EPIC is the school for intervention. Long waiting list.</p> <p>Tom: So quite okay lah and for those on waiting list to go to school one, they have therapy in KK but you know the appointment in KK is so many. By your next appointment, is few months already. By then you know in between what are you going to do, you don't know what to do.</p>
--	--	--	--

Appendix 3

Study 1 approval from Institutional Review Board (IRB)

Research Integrity and Ethics Office

Reg. No. 200004393R

IRB-2017-03-032-01

02 August 2017

Associate Professor Ring Joyce Pang Shu Min
School of Social Sciences

NTU INSTITUTIONAL REVIEW BOARD APPROVAL

Project Title: Pilot Study of Special Needs' Caregivers Questionnaire and Devising of Word Stimuli for adapted Multiple Disabled Implicit Association Test (MDIAT)

I refer to your application for ethics approval with respect to the above project.

The Board has deliberated on this application and accepted the change in:

1. Research site
2. Procedure

The Board is therefore satisfied with the bioethical considerations for the project and approves the ethics application.

A handwritten signature in black ink that reads "Lionel".

Professor Lionel Lee
Chair, NTU Institutional Review Board
encl.

Appendix 4

Consent form and Survey questions for Study 1

PARTICIPANT INFORMATION SHEET

- 1. Project title**
Special Caregivers in Singapore: Cognitive Appraisal and Expressed Emotion
- 2. Researcher and research supervisor(s), if any, with the contact number and organization.**

Researcher:

Michelle Nee Si Hui

Psychology M.A. Student

Nanyang Technological University

School of Humanities and Social Sciences

Mnee001@ntu.edu.sg

Tel: +65-81836908

Research Supervisor:

Dr. Joyce Pang Shu Min

Associate Professor

Nanyang Technological University,

HSS-04-08

School of Humanities and Social Sciences

JoycePang@ntu.edu.sg

Tel: +65 6790-6745

- 3. What is the purpose of this research?**

The aim of the study is to understand societal perception about children with special needs and the possible challenges of care-giving for them in Singapore. You are invited to participate in this study. This information sheet provides you with information about the project.

- 4. Who can participate in the research? What is the expected duration of my participation? What is the duration of this research?**

You will be eligible to participate if you are a parent, undergraduate or postgraduate over the age of 18 years old and am residing in Singapore. The entire study will take no longer than 30 minutes to complete.

You will only be asked to participate once and will not be contacted again by the researchers for further participation.

5. How will my privacy and the confidentiality of my research records be protected?

To protect your confidentiality, your data will be coded and no personal information of any form will be used to identify your response to the survey questions. None of your response will be connected with your name.

6. What are the possible discomforts and risks for participants?

The risks of participating in this study are minimal except a chance that you may feel fatigued from doing the survey and the nature of some of the questions may upset you. You also do not have to answer any question you feel uncomfortable with and can stop your participation at any time if you do not wish to continue.

7. What are the possible benefits to me and to others?

By participating, you are helping to contribute to scientific knowledge about an emerging field that has not been well explored in Singapore. The findings of the study will lead to scientific publications and may have the potential impact on policy-making for the caregivers of children with special needs in Singapore.

8. Can I refuse to participate in this research?

Yes, you can. Your decision to participate in this research is voluntary and completely up to you. You can also withdraw from the study at any time without giving any reasons, by informing the researcher.

9. Whom should I call if I have any questions or problems?

The researcher conducting this study is Michelle Nee Si Hui. You may ask any questions you have now by contacting her at mnee001.ntu.edu.sg or 65 8183-6908. Alternatively, you may also contact the researcher supervisor Dr. Joyce Pang Shu Min at 65 6790-6745 or JoycePang@ntu.edu.sg.

The study has been reviewed by the NTU Institutional Review Board for ethics approval. If you want an independent opinion of your rights as a research subject or if you have any complaints about this research study, you may contact the NTU Institutional Review Board at +65 6592-2495 or irb@ntu.edu.sg.

CONSENT FORM

Project: Pilot study on Special Caregivers in Singapore.

Researcher: Michelle Nee Si Hui

Research Supervisor: Dr. Joyce Pang Shu Min

I have been asked to take part in the Nanyang Technological University research project specified above. I have read and understood the Explanatory Statement and I hereby consent to participate in this project.

I consent to the following:	Yes	No
I agree to take part in the study.	☐	☐
The data that I provide during this research may be used by Nanyang Technological University	☐	☐

Date :

Part A. DEMOGRAPHIC INFORMATION

1) What is your age?

- 19-20 ☐ 21-29
- 30 – 39 ☐ 40 -49
- 50 – 59 ☐ 60 &above

2) Gender: ☐ Male ☐ Female

3) Please indicate your ethnicity.

- Chinese ☐ Malay ☐ Indian ☐ Others

4) What is your nationality?

- Singaporean ☐ PR ☐ EP / S Pass ☐
Foreigner

5) Please indicate your marital status.

☐ Single ☐ Married ☐ Divorced ☐ Widowed

6) Please indicate if you are a parent, undergraduate, postgraduate student or both.

☐ Parent ☐ Undergraduate ☐ Postgraduate ☐ Both a parent and current

undergraduate/ postgraduate

7) What is your highest educational level?

☐ Did not complete formal school ☐ PSLE ☐ O Level ☐ A Level

☐ Polytechnic diploma or equivalent ☐ Bachelor ☐ Post-graduate

8) Please indicate your institution.

☐ NTU ☐ NUS ☐ SMU ☐ SUTD ☐ SSS

☐ SIT ☐ Others

9) Please indicate your school/faculty.

- Engineering ☐ Science ☐ Humanities, Arts & Social Science
- Medicine ☐ Business ☐ Law
- Education ☐ Others

10) Do you know of anyone who is diagnosed with disability?

- Yes ☐ No

11) Which disability is he or she diagnosed with?

☐ Autism Spectrum Disorder ☐ Cerebral Palsy/Physical Disability ☐ Down Syndrome

☐ Intellectual Disability ☐ Others

11) Please indicate what condition is he/she diagnosed with.

12) What is your relationship with the person?

- Mother ☐ Father ☐ Grandmother ☐ Grandfather
- Relative ☐ Neighbor ☐ Friend

Part B. Open Ended Response

Write down 5 attributes or words (positive and negative) you think of/ associate with the following category of people. A definition of each disability has also provided for you.

a. Person with Autism Spectrum Disorder

Autism Spectrum Disorder: Autism is a developmental disability of the brain with currently no known causes or cures. Persons with autism largely have social skills problems in the areas of communication, interaction and integration.¹

Attributes (i.e. A person with Autism Spectrum Disorder is someone...)
1.
2.
3.
4.
5.

b. Person with Cerebral Palsy

Cerebral Palsy: Cerebral (brain) Palsy (lack of muscle control) is an inclusive term to describe a group of non-progressive disorders occurring in young children in which injury to the brain causes impairment of motor function.²

Attributes (i.e. A person with Cerebral Palsy is someone...)
1.
2.
3.
4.
5.

c. Person with Down syndrome

Down syndrome: A genetic condition that is caused by the presence of a particular chromosome, they tend to have mild to moderate intellectual disability, and possess easily recognizable facial characteristics.¹

Attributes (i.e. A person with Down Syndrome is someone...)
1.
2.

3.
4.
5.

d. Person with Intellectual Disability

Intellectual Disability: Intellectual disability is mainly characterized by a measure of their intelligence quotient, as well as limitations in their adaptive functioning. Some of these functions include academic functioning, social functioning and practical functioning.¹

Attributes (i.e. A person with Intellectual Disability is someone...)
1.
2.
3.
4.
5.

Part C. Questionnaires

The statements presented below express opinions or ideas about people with disabilities (mental, physical, visual, hearing). Many people agree and many disagree with each statement. I would like to know your opinion about them. Circle the appropriate number, from -3 to +3, which best corresponds with how you feel about the statement. There are no right or wrong answers.

	Strongly disagree	Pretty much disagree	A little disagree	A little agree	Pretty much agree	Strongly agree
1. People with disabilities get unfair advantages.	-3	-2	-1	+1	+2	+3
2. People with disabilities can increase their job skills through training.	-3	-2	-1	+1	+2	+3
3. Mental retardation and mental illness are similar.	-3	-2	-1	+1	+2	+3
4. Adults with developmental disabilities are in many ways like children.	-3	-2	-1	+1	+2	+3
5. People with disabilities should be encouraged to mainstream (engage in activities with non-disabled people).	-3	-2	-1	+1	+2	+3
6. I agree with the statement. "People with disabilities should be given more control in making decisions that affect their lives".	-3	-2	-1	+1	+2	+3
7. People with disabilities should live with others with similar disabilities.	-3	-2	-1	+1	+2	+3
8. I generally feel sorry for people with disabilities.	-3	-2	-1	+1	+2	+3
9. Adults with disabilities should not engage in sexual activities.	-3	-2	-1	+1	+2	+3
10. People with disabilities are not capable of making moral decisions.	-3	-2	-1	+1	+2	+3
11. Most people with disabilities are willing to work.	-3	-2	-1	+1	+2	+3
12. People with disabilities can be expected to fit into competitive society.	-3	-2	-1	+1	+2	+3
13. People with disabilities should be allowed to live where and how they choose.	-3	-2	-1	+1	+2	+3
14. People with disabilities are more emotionally maladjusted than the general public.	-3	-2	-1	+1	+2	+3
15. People with disabilities are able to adjust to life outside of an institutional setting.	-3	-2	-1	+1	+2	+3
16. Laws to prevent employers from discriminating against people with disabilities should be passed.	-3	-2	-1	+1	+2	+3

17. Simple and repetitive work is appropriate for people with disabilities.	-3	-2	-1	+1	+2	+3
18. The presence of a disabled in a social gathering makes people uncomfortable.	-3	-2	-1	+1	+2	+3
19. Disabled children in regular classroom have an adverse effect on other children.	-3	-2	-1	+1	+2	+3
20. The opportunity for gainful employment should be provided to people with disabilities.	-3	-2	-1	+1	+2	+3
21. People with disabilities can have an active social life.	-3	-2	-1	+1	+2	+3
22. People with disabilities are a financial drain and give little back to the community.	-3	-2	-1	+1	+2	+3
23. People with disabilities experience the same range of emotions as non-disabled people.	-3	-2	-1	+1	+2	+3
24. Some people with disabilities are physically indistinguishable from the general population.	-3	-2	-1	+1	+2	+3

Part D. Questionnaires (Scenario)

The following section are directed at those who have had experience taking care of with people with developmental disabilities, specifically children with

1. Autism Spectrum Disorders (ASD)
2. Cerebral Palsy
3. Down syndrome
4. Intellectual Disability

For students who do not have direct experience with people with developmental disability: Imagine someone in your family is diagnosed with developmental disability and you are now a caregiver for this population. Please stand in the viewpoint of a caregiver and indicate how you would feel. There are no right or wrong responses. It is best to note the first response that comes to mind.

	Strongly disagree	Disagree	Agree	Strongly Agree
1) I feel inferior because one of my family members has developmental disability.	1	2	3	4
2) I feel emotionally disturbed because I have a family member with developmental disability	1	2	3	4
3) The behaviour of my family member with developmental disability makes me feel embarrassed.	1	2	3	4
4) I feel helpless for having a family member with developmental disability	1	2	3	4
5) I feel sad because I have a family member with developmental disability	1	2	3	4
6) I worry if other people would know I have a family member with developmental disability.	1	2	3	4
7) I am under great pressure as I have a family member with developmental disability	1	2	3	4
8) Other people would discriminate against me if I am with my family member with developmental disability.	1	2	3	4
9) My reputation is damaged because I have a family member with developmental disability at home.	1	2	3	4
10) People's attitude towards me turns sour when I am with family member with developmental disability.	1	2	3	4
11) Having a family member with developmental disability imposes a negative impact on me.	1	2	3	4
12) Having a family member developmental disability makes me think that I am incompetent compared to other people.	1	2	3	4
13) Having a family member with developmental disability makes me think that I am lesser to others.	1	2	3	4
14) Having a family member with developmental disability makes me lose face.	1	2	3	4
15) I avoid communicating with family member with developmental disability.	1	2	3	4
16) I dare not to tell others that I have a family member with mental illness / intellectual disability.	1	2	3	4
17) Given that I have a family member with developmental disability, I've cut down the contacts with my friends and relatives.	1	2	3	4
18) When I am with _____ (name of family member with developmental disability, I would keep an especially low profile.	1	2	3	4
19) I've cut down the contacts with _____ (name of family member) developmental disability	1	2	3	4
20) I dare not to participate in activities	1	2	3	4

related to developmental disability lest other people would suspect that I have a family member with developmental disability.

21) Given that I have a family member with developmental disability, I've cut down the contacts with my neighbours.	1	2	3	4
---	---	---	---	---

Family Questionnaire (FQ) (Expressed Emotion)

	Never/Very Rarely	Rarely	Often	Very Often
1) I tend to neglect myself because of him/her.	1	2	3	4
2) I have to keep asking him/her to do things.	1	2	3	4
3) I often think about what is to become of him/her.	1	2	3	4
4) He/she irritates me.	1	2	3	4
5) I keep thinking about the reasons for his/her illness.	1	2	3	4
6) I have to try not to criticize him/her.	1	2	3	4
7) I can't sleep because of him/her.	1	2	3	4
8) It's hard for us to agree on things.	1	2	3	4
9) When something about him/her bothers me, I keep it to myself.	1	2	3	4
10) He/she does not appreciate what I do for him/her.	1	2	3	4
11) I regard my own needs as less important.	1	2	3	4
12) He/she sometimes gets on my nerves.	1	2	3	4
13) I'm very worried about him/her.	1	2	3	4
14) He/she does some things out of spite.	1	2	3	4
15) I thought I would become ill myself.	1	2	3	4
16) When he/she constantly wants something from me, it annoys me.	1	2	3	4
17) He/she is an important part of my life.	1	2	3	4
18) I have to insist that he/she behave differently.	1	2	3	4
19) I have given up important things in order to be able to help him/her.	1	2	3	4
20) I'm often angry with him/her.	1	2	3	4

You have completed the questionnaire.

Please complete the following if you wish to be contacted/informed about the results and follow-up study.

Email Address: _____

Thank you for your participation!

Appendix 5

Study 2 approval from Institutional Review Board (IRB)

IRB-2017-03-031-01

12 December 2017

Associate Professor Ring Joyce Pang Shu Min
School of Social Sciences

NTU INSTITUTIONAL REVIEW BOARD APPROVAL

Project Title: Informal Caregiver's Cognitive Appraisal on Expressed Emotion towards Child with Disabilities

I refer to your application for ethics approval with respect to the above project.

The Board has deliberated on this application and accepted the change in:

1. Procedures
2. Informed consent

The Board is therefore satisfied with the bioethical considerations for the project and approves the ethics application.

A handwritten signature in black ink, appearing to read 'Lionel Lee'.

Professor Lionel Lee
Chair, NTU Institutional Review Board
encl.

Appendix 6

Study 2 letter of indemnity

School of Social Sciences

November 20, 2017

Letter of indemnity

Dear Sir/Madam:

I am writing on behalf of NTU Psychology Master student, Ms Michelle Neo. I believe that she is in discussion with your organization for a possibility of collaboration and outreach to potential participants.

Michelle's Masters research topic is on the psychological and emotional correlates of health and well-being for caregivers of children with developmental disabilities. As such, she is interested in a very selective sample. As far as I know, there has not been any research project looking specifically at the topic she is investigating and her research has the potential to contribute to public awareness as well as academic knowledge of the caregiving community.

It would be very helpful to Michelle if you would kindly be able to assist her in reaching out to potential participants. All of her research protocols have been approved by the IRB and cleared for proper ethical conduct, and I will personally see to it that she is both respectful and grateful in her interactions with all caregivers.

Thank you for your kind consideration.

Sincerely,

A handwritten signature in black ink, appearing to be "Ring Joyce Pang Shu Min".

Assoc Prof. Ring Joyce Pang Shu Min
Head, Psychology Program
Nanyang Technological University
School of Social Sciences.

Assoc Prof Joyce Pang Shu Min
Head, Psychology
School of Social Sciences

Appendix 7

Study 2 brochure

Special Caregivers in Singapore: Cognitive Appraisal and Expressed Emotion.

M.A. Thesis Study (Division of Psychology, NTU)

Aims & Objectives

1. To understand the influence of cognitive appraisal (degree of affiliate stigma and implicit prejudice) of caregivers on attitude towards child with developmental disability (e.g. Autism Spectrum Disorder, Cerebral Palsy, Down Syndrome, Intellectual Disability, ADHD)
2. To explore the interaction of caregiver's cognitive appraisal between caregiver burden and caregiver's subjective well-being.
3. To assess the importance of different type of social support on expressed emotions.

Format of study

- Face-to-face semi-structured interview and questionnaire
- Non-invasive, conducted at caregiver's preferred time and location
- Single session, no more than 2 hours.
- \$30 cash as a form of incentive.

Significance

- High relevance to Singapore's society, given high prevalence of developmental disability diagnosis among children.
- Little study conducted in Singapore about caregiver population of children with special needs.
- Expressed Emotions may be undetected, but its effect is detrimental for both child and family subjective being.
(Reliable association of parental expressed emotion with children's behaviour problems)

Implications

- Enhanced understanding of cognitive appraisal and influence towards expressed emotions during caregiver-child dyadic interaction → Could help in the tailoring or fine-tuning of interventions available in upcoming Disability Caregiver Support Centre.

Appendix 8

Study 2 consent form

Informal Caregiver's Cognitive Appraisal on Expressed Emotion towards Child with Developmental Disabilities/Difficulty in Singapore

Title of Study

Interview study – Special Caregivers in Singapore

Purpose of the Study

I am interested in understanding the dynamics of caregiving for children with developmental disabilities in Singapore. I invite you to participate in this study which will take no longer than 90minutes.

My purpose is to build an understanding of how caregiver's history and thoughts affect caregiving process, to understand why some caregiver display more expressed emotions towards child, whereas other caregivers do not.

Specifically, I am interested in the following major **themes**:

1. RQ1 Implicit Prejudice and Affiliate Stigma: How does the preconception of developmental disability influence caregiver's thinking about child?
2. RQ2 Caregiver Burden and Subjective Wellbeing: What is the impact of caregiving on caregiver's mental health?
3. RQ3 Interaction with child and Expressed Emotions: Do caregivers suppress their emotions around child? How might emotion regulation affect caregiver-child bonding/ interaction
4. RQ4 Role of social support: Is there presence of sufficient social support? How does social support help in caregiving situation?

Procedures

If you decide to take part in this research by giving your permission to the interviewer, you will be invited to take part in the study. The study will take place at a preferred location of your choice (home setting with your consent/ community setting) and a one-to-one session will be conducted with you. This study will comprise of a semi-structured interview and an online survey. The entire interview session is expected to last for no longer than 90minutes. The interviews will be audiotaped and transcribed for analysis.

Risks and Discomforts

There are minimal risks for engaging in an experience sharing session. You will experience no more risk than you would encounter in daily life.

Potential Benefits

Your participation in this study will bring about the opportunity for you to share your experience, as well as to reflect on the various factors and challenges you have encountered in the process of caregiving. Your participation will also contribute to our understanding of an emerging field that has not been well explored in Singapore. The findings of the study will lead to scientific publications and have the potential impact on policy-making for the caregivers of children with special needs in Singapore. It will also help contribute to building a repository platform of reading resources for caregivers in the future.

Confidentiality

All personal information and responses provided by you in the study will be treated as strictly confidential. Study data and audio records of the interview sessions will be stored securely, under lock and key for 10 years and will be made available only to members of the research team. In follow-up reports and publications, your identifying information will be obscured or omitted.

Right to Refuse or Withdraw

Your participation is voluntary. This means that you can choose to stop at any time without negative consequences.

Compensation

As a token of appreciation, you will receive \$30 at the end of the session. A summarised copy of the findings will also be made available to you if you are interested.

Questions and Concerns

If you have any questions about this study, please contact Ms Michelle Nee Si Hui. You contact her at michellenee4@gmail.com. The study has been reviewed by the NTU Institutional Review Board for ethics approval. If you have questions regarding your rights as a research participant, please contact the Institutional Review Board of Nanyang Technological University at +65 6592-2495 or irb@ntu.edu.sg.

SIGNATURE

I _____ (Name of Participant) understand the procedures described above and agree to participate in this study.

I agree / do not agree to the audio-recording during the procedure.

Signature of Participant

Date: _____

Name & Signature of Researcher/Interviewer

Date: _____

Subject Payment Details

SIGNATURE

I _____ (Name of Participant) hereby acknowledge that I have been paid \$30 in the form of cash.

Signature of Participant

Date: _____

Name & Signature of Researcher/Interviewer

Date: _____

Appendix 9

Study 2 questionnaire

DEMOGRAPHIC INFORMATION

- 1) Gender: ☐ Male ☐ Female
- 2) Age: ☐ 21 – 30 ☐ 31 -40 ☐ 41 – 50 ☐ 51 – 60
☐ 60 & above
- 3) Marital status: ☐ Single ☐ Married ☐ Divorced ☐ Widowed
- 4) Ethnicity: ☐ Chinese ☐ Malay ☐ Indian ☐ Others
- 5) Are you a: ☐ Singaporean ☐ PR ☐ EP / S Pass ☐ Foreigner
- 6) What is your relation to the child?
- Mother ☐ Father ☐ Grandmother ☐ Grandfather ☐ Relative
 - Professional Caregiver ☐ Domestic helper
- 7) Which developmental disability is your child diagnosed with? (Please tick the primary diagnosis/ most relevant one).
- ☐ Autism Spectrum Disorder ☐ Cerebral Palsy ☐ Down Syndrome
- ☐ Intellectual Disability
- 8) What is your housing type?
- ☐ Landed/Private condo ☐ HDB 5room/Executive ☐ HDB 3-4room
- ☐ HDB 1-2 room ☐ HDB Rental Flat
- 9) What is your highest educational level?
- Did not complete formal school ☐ PSLE
 - O Level ☐ A Level
 - Polytechnic diploma or equivalent ☐ Bachelor
 - Post-graduate
- 10) What is your current working status?
- Employed, working part-time ☐ Employed, working full-time

- Self-employed
- Unemployed
- Retiree

11) Besides caring for CWD, do you have any other family members to take care of (i.e. children/ elderly parents)?

- Yes, I am also a primary caregiver for both my children and parents.
- Yes, I am also a primary caregiver for my other children.
- Yes, I am also a primary caregiver for my parents.
- No, I am only a primary caregiver for CWD.

Section A

The statements presented below express opinions or ideas about people with disabilities (mental, physical, visual, hearing). Many people agree and many disagree with each statement. I would like to know your opinion about them. Circle the appropriate number, from -3 to +3, which best corresponds with how you feel about the statement. There are no right or wrong answers.

	Strongly disagree	Pretty much disagree	A little disagree	A little agree	Pretty much agree	Strongly agree
1. Adults with developmental disabilities are in many ways like children.	-3	-2	-1	+1	+2	+3
2. I agree with the statement. “People with disabilities should be given more control in making decisions that affect their lives”.	-3	-2	-1	+1	+2	+3
3. I generally feel sorry for people with disabilities.	-3	-2	-1	+1	+2	+3
4. People with disabilities can be expected to fit into competitive society.	-3	-2	-1	+1	+2	+3
5. People with disabilities should be allowed to live where and how they choose.	-3	-2	-1	+1	+2	+3

6. People with disabilities are more emotionally maladjusted than the general public.	-3	-2	-1	+1	+2	+3
7. People with disabilities are able to adjust to life outside of an institutional setting.	-3	-2	-1	+1	+2	+3
8. Laws to prevent employers from discriminating against people with disabilities should be passed.	-3	-2	-1	+1	+2	+3
9. Simple and repetitive work is appropriate for people with disabilities.	-3	-2	-1	+1	+2	+3
10. The presence of a disabled in a social gathering makes people uncomfortable.	-3	-2	-1	+1	+2	+3
11. The opportunity for gainful employment should be provided to people with disabilities.	-3	-2	-1	+1	+2	+3
12. People with disabilities are a financial drain and give little back to the community.	-3	-2	-1	+1	+2	+3

Section B

This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the patient in this way. There are no right or wrong responses. It is best to note the first response that comes to mind.

	Strongly disagree	Disagree	Agree	Strongly Agree
1) The behaviour of my child makes me feel embarrassed.	1	2	3	4
2) I worry if other people would know I have a child with developmental disability.	1	2	3	4
3) My reputation changes because of my child.	1	2	3	4
4) People's attitude towards me changes when I am with my child.	1	2	3	4
5) Having a child with developmental disability imposes a negative impact on me.	1	2	3	4
6) Having a child with developmental disability makes me think that I am lesser to others.	1	2	3	4

7) Having a child with developmental disability makes me lose face.	1	2	3	4
8) I avoid communicating with my child in public.	1	2	3	4
9) I dare not to tell others that I have a child with developmental disability.	1	2	3	4
10) I've cut down the contacts with my friends and relatives.	1	2	3	4
11) When I am with family member with developmental disability, I would keep an especially low profile.	1	2	3	4
12) I dare not to participate in activities related to developmental disability lest other people would suspect that I have a family member with developmental disability	1	2	3	4
13) I've cut down the contacts with my neighbours.	1	2	3	4

Section C

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

	Very Strongly Disagree	Strongly Disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very Strongly agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
	Very Strongly Disagree	Strongly Disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very Strongly agree
5. I have a special person who is a real	1	2	3	4	5	6	7

source of comfort to me.

6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Section D

Please think back over the past month and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time.

	Not at all	A little	Somewhat	Quite a bit	Very much
1. Interruption of personal time resulting from your child's emotional or behavioural problem?	1	2	3	4	5
2. You missing work or neglecting other duties because of your child's emotional or behavioural problem?	1	2	3	4	5
3. Financial strain for your family as a result of your child's emotional or behavioural problem?	1	2	3	4	5
4. Disruption or upset of relationships within the family due to your child's emotional or behavioural problem?	1	2	3	4	5

5. How sad or unhappy did you feel as a result of your child's emotional or behavioural problem?	1	2	3	4	5
6. How worried did you feel about your child's future?	1	2	3	4	5
7. How tired or strained did you feel as a result of your child's emotional or behavioural problem?	1	2	3	4	5

Section E

The following questions ask how satisfied you feel, on a scale from zero to 10. **Zero** means you feel no satisfaction at all and **10** means you feel completely satisfied.

1. "How satisfied are you **with your standard of living?**"

Completely satisfied								No satisfaction at all
0	1	2	3	4	5	6	7	8 9 10

2. "How satisfied are you **with your health?**"

Completely satisfied								No satisfaction at all
0	1	2	3	4	5	6	7	8 9 10

3. "How satisfied are you **with what you are achieving in life?**"

Completely satisfied								No satisfaction at all
0	1	2	3	4	5	6	7	8 9 10

4. "How satisfied are you **with your personal relationships?**"

Completely satisfied								No satisfaction at all
0	1	2	3	4	5	6	7	8 9 10

5. "How satisfied are you **with how safe you feel?**"

Completely satisfied								No satisfaction at all
0	1	2	3	4	5	6	7	8 9 10

6. "How satisfied are you **with feeling part of your community?**"

Completely satisfied								No satisfaction at all
0	1	2	3	4	5	6	7	8 9 10

7. "How satisfied are you **with your future security?**"

Completely satisfied								No satisfaction at all
0	1	2	3	4	5	6	7	8 9 10

Section F

This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the child in this way. There are

no right or wrong responses. It is best to note the first response that comes to mind. Please respond to each question, and mark only one response per question.

	Never/Very Rarely	Rarely	Often	Very Often
1) I tend to neglect myself because of him/her.	1	2	3	4
2) He/she irritates me.	1	2	3	4
3) When something about him/her bothers me, I keep it to myself.	1	2	3	4
4) He/she does not appreciate what I do for him/ her.	1	2	3	4
5) I regard my own needs as less important.	1	2	3	4
6) He/she sometimes gets on my nerves.	1	2	3	4
7) I'm very worried about him/her.	1	2	3	4
8) When he/she constantly wants something from me, it annoys me.	1	2	3	4
9) I have given up important things in order to be able to help him/her.	1	2	3	4
10) I'm often angry with him/her.	1	2	3	4

You have completed the questionnaire. Thank you for your participation!

Appendix 10

Interview guide

The interviews will be semi-structured (Smith 2003) and the style is non-directive to elicit narratives characterized by what was most prominent for the parent in everyday life with their child at the time. The aim of the interview was to obtain an image of parents' perceptions and subjective experiences, with the following research questions:

RQ1 Implicit Prejudice and Affiliate Stigma: How does the preconception of developmental disability influence caregiver's thinking about child?

RQ2 Caregiver Burden and Subjective Wellbeing: What is the impact of caregiving on caregiver's mental health?

RQ3 Interaction with child and Expressed Emotions: Do caregivers suppress their emotions around child? How might emotion regulation affect caregiver-child bonding/interaction?

RQ4 Role of social support: Is there presence of sufficient social support? How does social support help in caregiving situation?

Bearing the research questions in mind, the interview questions focused on four main themes: (1) present life situation (describing an ordinary day; What works well/less well in your everyday life?); (2) stigmatizing experiences; (3) changes (Are you trying to change anything in your everyday life? What have you learnt from being a parent to your child?); (4) expectations (How does your present life situation match your expectations?); and (5) the future (What are your expectations and dreams for the future, short and long term?). The questions were followed by 'minimal probes' (Smith & Osborn 2003) when needed. In addition, a five-minute speech sample will be added to evaluate caregiver's expressed emotions towards child.

The following questions serve as a guide for the interview.

(1) Present life situation

Describing an ordinary day

- What works well/less well in your everyday life? (Challenges and solutions)
- Feelings that you experience daily
- Do you bring child out to meet friends? (If no, why not?)

- How is the interaction between you and your child like?
Describe the interaction with your child. Do you and your child get along?
- How would you describe your child? (Related to expressed emotions)**
- Reactions to child when child misbehaves/ do not listen to you; feelings and enacted behaviour
 - Are there have days where you are so stressed up? How do you manage the stress? When interacting with your child, are there instances where you share/reveal your emotions?
- (2) Stigmatizing experience
- Have you encounter any stigmatization by the public? / **Are you aware of any stigma that public has of you or your child?**
 - Any examples to highlight the experience?
 - How do you feel when encountered with it?
 - How do you go about addressing the stigma?
 - **Do you feel any of these stigmas about yourself as a parent? Do these stigmas affect you personally? Why or why not? (Related to affiliate stigma)**
- (3) Changes before and after caregiving
- a. **What are some of the changes you experience both physically and emotionally as you become the primary caregiver? How do you feel about these changes?**
 - b. Any changes in personal lifestyle/habits?
 - c. Any change in social support/friend?
 - d. Any changes of your personal image in public? How do you think society and family view you as an individual/caregiver (Related to affiliate stigma)?
 - e. **Role expectations? (I.e. What do you think is your role as a caregiver?)**
 - f. What have you learnt from being a caregiver to child?
 - g. **Growing up, what was your perception of children with special needs? Now that you are a caregiver, is there any change in perception? (Related to implicit prejudice) Do you think your pre-existing perception influences your thought process while providing care?**
- (4) Expectations
- a. **How does your present life situation match your expectations?**
 - b. Any changes that you made to bridge the gap? (Narrowing incongruence)
 - c. **In your opinion, is there sufficient social support resources available for you?**
- (5) Future
- a. What are your expectations and dreams for the future, short and long term? (In relation to societal expectation and envision for caregiver-child interaction)
 - b. What can be done further to help alleviate caregiving burden/ misconceptions society has towards child?