The Experiences of Parents in Providing Behaviour Support To Children With Autism Spectrum Disorder in Quang Binh, Vietnam

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DECLARATION

I certify that this dissertation does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university, and that to the best of my knowledge and belief it does not contain any material previously published or written by another person, except where due reference is made to the text.

Signed:  Date: 25 June 2019

Primary Supervisor's Certification

I confirm that I have approved all aspects of the research project in this thesis, including the content of the literature review, data collection, analysis, reporting and data storage.

Primary Supervisor Signed:  Date: 25 June 2019

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ACRONYMS

AEPD: Association for Empowerment of Persons with Disabilities

APA: American Psychiatric Association

ASD: Autism Spectrum Disorder

Dong Hoi Centre: Dong Hoi Centre for Caring and Educating Children with Disabilities

SBREC: Flinders University Social and Behavioural Research Ethics Committee

WHO: World Health Organisation

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ABSTRACT

Background and Aims: There is a high occurrence of challenging behaviours among children with Autism Spectrum Disorder (ASD). Parents are often the primary caregivers of children with ASD, and therefore play a key role in providing behaviour support. There has been considerable research regarding ASD and behaviour support; however, there is limited research in this area in developing countries, including Vietnam, and no research examining the lived experiences of parents in providing behaviour support to children with ASD in Quang Binh, a small province in Vietnam. This research aims to address this gap in the literature by providing preliminary insights into experiences of parents in Quang Binh, which is important to better understand parents' perspectives to inform services to best meet their support needs.

Methodology: A qualitative phenomenological approach was utilised, consisting of semi-structured interviews with 10 parents living in Quang Binh who have a child with ASD. Interviews were audio recorded, transcribed and thematically analysed using NVivo. Ecological systems theory was utilised as a guiding framework to present and discuss the research findings.

Results: Parents' strengths identified in providing behaviour support included the use of preventative strategies (e.g., environmental modification). Parents also reported a sense of responsibility and unconditional love for their child, which were considered key foundations in providing effective behaviour support. Parents reported significant barriers in accessing relevant supports and services, with the following key themes identified: 'limited knowledge regarding ASD and behaviour support', 'financial burden', 'time-limitations' and 'stigma and cultural attitude'. Parents received support through family, social networks and professionals; however, their perception of these supports varied, with some parents reported this to be unhelpful specific to behaviour support. The need for more information and accessible and affordable support services relating to ASD and behaviour support were emphasised by all ten participants.

Conclusions: In using the ecological systems theory, it was evident that the experiences of parents were impacted across system levels, including the microsystem, mesosystem, exosystem and macrosystems. Synthesis of findings in this research highlights a lack of expertise in behaviour support in Quang Binh, Vietnam. Findings were discussed in the broader context of Vietnam, with recommendations for further research to inform an optimal service model, including policies and best-practices in providing behaviour support for individuals with ASD and their families in a Vietnamese context.

CHAPTER 1
INTRODUCTION

1.1 Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by difficulties in social communication, repetitive behaviours, interests and sensory sensitivities (American Psychiatric Association, 2013). Many studies have suggested that ASD may be associated with genetic and environmental factors (Kliegman, Schor, St Geme, & Stanton, 2015; Volkmar & Wiesner, 2009); though universally accepted causes of ASD are yet to be determined. The prevalence of ASD is increasing globally (Fombonne, 2005, 2009; World Health Organization [WHO], 2014); however, the exact figure remains uncertain, with figures representing about 1 in 160 children (WHO, 2014). An individual with ASD may experience frustration and difficulties expressing unmet needs due to his/her limited formal communication and sensory processing that are not well understood by people in their environment. As a result, behaviours may be challenges for the individual, their family and support systems. However, there is evidence that if understood and supported by people and the environment, many individuals with ASD can manage and achieve meaningful relationships, education and employment (American Psychiatric Association, 2013).

The high prevalence of challenging behaviours have been reported amongst children with ASD (Buschbacher & Fox, 2003; Horner, Carr, Strain, Todd, & Reed, 2002; Tonge, Bull, Brereton, & Wilson, 2014). It is estimated that nearly 94.3% of children with ASD present at least one challenging behaviour (Matson, Mahan, Hess, Fodstad, & Neal, 2010; Matson, Wilkins, & Macken, 2009). These may manifest in a variety of ways, including physical and verbal aggression (Kanne & Mazurek, 2011), repetitive motor behaviours (Reid, Parsons, & Lattimore, 2010), self-injury (Matson & Turygin, 2012) and property destruction (Luby, 2011). These behaviours may emerge in early childhood and persist throughout an individual's life, having a significant impact on the child and their family

(Doubet & Ostrosky, 2015; Fox, Dunlap, & Powell, 2002; Osborne & Reed, 2008; Safe, Joosten, & Molineux, 2012; Woodgate, Ateah, & Secco, 2008).

A growing body of research regarding ASD, challenging behaviours and behaviour support has been undertaken in English countries (Safe et al., 2012; Samadi & McConkey, 2014). This may reflect the significant impacts that these behaviours have on parents of children with ASD (Cummins, 2001; Fettig, Schultz, & Ostrosky, 2013; Prior & Roberts, 2012; Roberts, Williams, Smith, & Campbell, 2016). Previous studies found that high levels of stress and reduced emotional wellbeing among parents of children with ASD were related to the child's occurrence of challenging behaviours (Osborne & Reed, 2008; Woodgate et al., 2008).

Meanwhile, research on ASD and behaviour support is limited in developing countries, including Vietnam. The current literature relating to ASD in Vietnam includes assessment and diagnosis of ASD in Hanoi (Vu, Whittaker, & Rodger, 2017), living with ASD in Vietnam (Motchan, 2012), parenting stress and coping styles of parents of children with ASD (Luong, Yoder, & Canham, 2009). No specific peer reviewed research on parents' experiences in providing behaviour supports to children with ASD in Quang Binh was found during extensive literature searches.

Quang Binh is a small province located in central Vietnam, with a population of 882,505 (Quang Binh Provincial Committe Office, 2017). According to Quang Binh Department of Labour, Invalids and Social Affairs (Pham, 2018), there are approximately 4,500 children living with disabilities in this province, children with ASD accounting for 15%. It is reported that the majority of these children live at home with their families, who may face significant challenges in providing daily support in addition to the behaviour support required (Pham, 2018).

1.2 Research Aims and Research Questions

This research aims to address the gap in the literature by providing preliminary insights into parents' lived experiences in providing behaviour support to their child. This is important to better understand parents' perspectives to inform services to best meet their support needs.

Specifically, this research will address the following research questions:

(1) What are the strengths and challenges experienced by parents in providing behaviour support to their children with ASD?
(2) What supports are families receiving, and what are their support needs specific to providing behaviour support to their children with ASD?

1.3 Structure of Dissertation

The structure of this thesis is as follows:

Chapter 2: Literature Review: The relevant literature will be presented to provide a foundation of key issues raised though this thesis relating to behaviour support for children with ASD, and the issues specific to providing this support within a Vietnamese context.

Chapter 3: Methodology: The methods used to address the research aims and research questions will be presented.

Chapter 4: Results: Findings will be presented, including themes and quotes related to research objectives.

Chapter 5: Discussion and Conclusion: The findings of this research will be critically discussed according to the research aims and the ecological system theory. The research strengths and limitations, and recommendations for policy, practice and future research will also be presented.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

This chapter discusses relevant literature to provide a foundation of the issues raised through this thesis relating to behaviour support for children with ASD, and the issues specific to providing this support within a Vietnamese context. A brief overview of ASD and challenging behaviours is provided, followed by a discussion examining the impacts of challenging behaviours on children with ASD and their parents. This chapter will then present behaviour support strategies commonly being used by families, and their support needs in providing this support to children with ASD.

2.2 An overview of Autism Spectrum Disorder

Autism Spectrum Disorder is a neurodevelopmental disorder that is complex to define and diagnose (Buron & Wolfberg, 2014). According to the latest version of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) (APA, 2013), ASD is defined by 'persistent deficits in social communication and social interaction across multiple contexts; and restricted, repetitive patterns of behaviours, interests, or activities' (p.50-51). The diagnostic criteria include a wide range of ASD symptoms from mild to severe levels on the spectrum, which provides a clear description and organisation of key characteristics (Buron & Wolfberg, 2014). Further, the DSM-5 stresses the dimensional nature of ASD, allowing professionals to assess the needs of the individuals and design appropriate support plans (Lai, Lombardo, & Baron-Cohen, 2014; Wheeler, Mayton, & Carter, 2015). Importantly, the DSM-5 definition is widely accepted internationally in developed countries and in the literature (Buron & Wolfberg, 2014). The diagnosis and assessment of ASD typically starts with early recognition, followed by referral to a multidisciplinary team including a psychologist and a psychiatrist or a physician (Hall, 2013b) .

In Vietnam, the number of children diagnosed with ASD increased significantly, from 450 in 2008 to 2468 in 2014 (Dau & Vu, 2015); though, there are still significant challenges in understanding, assessing and diagnosing ASD (Motchan, 2012; Vu et al., 2017; Ying, Browne, Hutchinson, Cashin, & Bui, 2012). ASD in Vietnam has been only recognised and diagnosed since the late 1990s and early 2000s at the National Hospitals of Paediatrics based in Hanoi and Ho Chi Minh City – the two biggest cities of Vietnam (Vu et al., 2017). ASD is currently not categorised as a type of specific disability in the National Law on People with Disabilities (National Assembly of Vietnam, 2010). Further, there are no current books about ASD printed in Vietnamese. Previous studies on ASD in Vietnam revealed that assessing and diagnosing were challenged by 'rushed' and insufficient assessment, a shortage of assessment guidelines, limited communication among professionals in assessment teams and between professionals and families of children with ASD (Motchan, 2012; Vu et al., 2017; Ying et al., 2012).

2.3 Challenging behaviours in children with ASD

Challenging behaviour is defined as behaviour that affects the individual's quality of life and his/her ability to pursue dignity and/or rights and causes risks to his/her safety and/or other's (Machalicek et al., 2016; McVilly, Bristow, Foreman, Goddard, & Australian Society for the Study of Intellectual Disability, 2002). This may include, but is not limited to physical and verbal aggression (Kanne & Mazurek, 2011; Murphy, MacDonald, Hall, & Oliver, 2000); repetitive motor behaviours/stereotypes (Loftin, Odom, & Lantz, 2008; Reid et al., 2010); "noncompliance" (Donohue, Casey, Bicard, & Bicard, 2012); self-injury (Matson & Turygin, 2012; Minshawi et al., 2014); property destruction (Luby, 2011); and, "tantrums" or "meltdown" (Jang et al., 2013).

Children with ASD are reported to exhibit challenging behaviours that present in early childhood and could continue throughout their later life (Green, O'Reilly, Itchon, & Sigafoos, 2005; Hattier, Matson, Belva, & Horovitz, 2011; Rzepecka, McKenzie, McClure, & Murphy, 2011; Williams, Armstrong, Agazzi, & Bradley-Klug, 2010). This was highlighted by a study conducted by Green et al. (2005), which examined the persistence of challenging behaviours in 13 children with developmental disabilities including ASD

over three years. All children were reported to present a high prevalence of challenging behaviours including aggression, self-harm, property destruction and tantrums at the beginning of the study. These behaviours were then monitored and evaluated every six months by teachers using the Aberrant Behaviour Checklist (Aman & Singh, 1986). Very few changes in challenging behaviours were reported among participants (9/13 children) over the three-year period. Findings from the study by Green et al. (2005) were supported by a study by Hattier et al. (2011), which has also found that the occurrence of challenging behaviours in children with ASD was significantly higher in comparison to their peers with non ASD impairments (Hattier et al., 2011). Without timely and appropriate interventions, challenging behaviours often result in long-term impacts on the child and their families (Burbach, Fox, & Nicholson, 2004; Williams et al., 2010).

In summary, challenging behaviours in children with ASD and its prevalence are broadly reported in research in Western countries. Previous research on children with ASD in Vietnam, however, has mainly focussed on the diagnosis of ASD, educational needs and impacts of living with ASD on children with ASD and their parents (Motchan, 2012; Vu et al., 2017; Vu, Whittaker, Whittaker, & Rodger, 2014). There has been a lack of research on challenging behaviours on children with ASD and parents' experiences in providing behaviour support to their child. Thus, conducting this study will contribute to reducing this gap in the literature. Given the limited Vietnamese-specific literature, the following discussions will be inclusive of broader literature to provide insight into key issues relating to impacts of challenging behaviours on children with ASD and their parents and strategies being used by parents in providing behaviour support to their child.

2.4 Impacts of challenging behaviours

2.4.1 Impacts on the individuals

Challenging behaviours can negatively impact a child's development, education and social inclusion (Gilliam & Shahar, 2006; Mendez, Fantuzzo, & Cicchetti, 2002; Neilsen & Mcevoy, 2004; Safe et al., 2012). Children with ASD and challenging behaviours are often reported to be excluded from educational settings (DePape & Lindsay, 2015; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Safe et al., 2012). It has been suggested

that this may be due to educators (Divan et al., 2012), who as a result of limited professional expertise and access to training, may make inappropriate judgements regarding the child's educational outcomes (DePape & Lindsay, 2015). The potential exclusion of children with ASD in education settings was further emphasised in a qualitative study conducted by Penney (2013), in which interviews were conducted with nine parents of young adults with ASD and four young people with ASD to explore the school-related issues for young individuals with ASD and co-occurring depression and/or anxiety disorders. One of the parents in this study (Penney, 2013) reported that their child was often removed from their school due to the child's challenging behaviours:

> *They would remove him from the classroom, but they would call us all the time. … A lot of the times as well as though they would remove him from the classroom, and they would call us and let us know that he was screaming and shouting and shouting and whatever he was doing. In junior high, often we had to come and get him (Penney, 2013, p. 82)*

Educational exclusion could subsequently lead to the child's poor academic achievements and significant delays in social skill development further exacerbating social isolation and increasing anxiety (Machalicek et al., 2016; Macintosh & Dissanayake, 2006; Mendez et al., 2002; Neilsen & Mcevoy, 2004).

In terms of social inclusion, research suggests that children with ASD experience discrimination from professional services and in public places (Ludlow, Skelly, & Rohleder, 2012; Safe et al., 2012; Woodgate et al., 2008). Children with ASD were perceived to be 'misbehaving' by strangers in public places, which is consistent with enacted stigma (Gray, 1993). This is a reflection of cultural values, where children with challenging behaviours are seen as 'second class human being' (Crabtree, 2007, p. 56). In another study by DePape and Lindsay (2015), the authors conducted a thematic synthesis to explore the experiences of parents caring for a child with ASD. DePape and Lindsay (2015) found that parents of children with ASD experienced criticism from community members towards their child.

There has been a lack of specific and focussed research on the impacts of challenging behaviours in children with ASD in Quang Binh province and Vietnam. The only study found in the literature around reported impact of challenging behaviour on families was conducted in Hanoi to examine the life, experiences and needs of children with ASD through photovoice (Vu & Whittaker, 2016). Children with ASD were instructed to take photographs of their daily activities and their engagement in both parent-set up school and home settings. The majority of children participating in the study (72%) took photos within their house. There were only 4% of these photos that related to events, places or activities organized specifically for individuals with ASD. The study by Vu and Whittaker (2016) found that children with ASD were socially and physically excluded from the outside world. Although the Vu and Whittaker (2016) study did not highlight a relationship between challenging behaviours and social isolation among children with ASD, it could certainly be hypothesised that this social isolation would have an impact on their behaviour. This is a worthy research topic for future studies.

2.4.2 Impact on family

Previous literature conducted in developed countries has reported that parents of children with ASD and challenging behaviours experienced a high level of stress (Argumedes, Lanovaz, & Larivée, 2018; Divan et al., 2012; Doubet & Ostrosky, 2015; Safe et al., 2012; Samadi & McConkey, 2014; Wang, Michaels, & Day, 2011). Rivard, Terroux, Parent-Boursier, and Mercier (2014) researched 236 parents of children with ASD in Quebec, Canada, to explore factors causing their stress. Results from Rivard et al. (2014) study showed that stress of parents of children with ASD was associated with their child's challenging behaviours and support needs. In agreement with Rivard et al. (2014), Argumedes et al. (2018) released a brief report on the impact of challenging behaviours on parenting stress in mothers and fathers in Canada. 42 families in the study of Argumedes et al. (2018) were asked to complete measures including the Childhood Autism Rating Scale (CARS-2) (Schopler, Van Bourgondien, Wellman, & Love, 2002), the Behaviour Problem Inventory (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001) and the Parenting Stress Index-3rd edition (Abidin, 1995). Argumedes et al. (2018) found that

parents' increased stress was associated with the increase in the severity of ASD and challenging behaviours presented by their child.

Parental relationships may also be strained as a result of caring a child with ASD and challenging behaviours (Bessette Gorlin, McAlpine, Garwick, & Wieling, 2016; Bilgin & Kucuk, 2010; Freedman, Kalb, Zablotsky, & Stuart, 2012; Meirsschaut, Roeyers, & Warreyn, 2010; Phelps, Hodgson, McCammon, & Lamson, 2009). In 2009, Phelps and colleagues analysed qualitative data from 80 parents to explore their experiences in caring for a child with ASD. Their analysis revealed that parents' relationship with their partners was strained due to different parenting styles and the limited time allocation to each other. Findings from Phelps et al. (2009) are consistent with a study by Bilgin and Kucuk (2010), who also found strained relationships in parents of children with ASD. Conflicts around parenting strategies coupled with stress reportedly led to a significant breakdown of the family relationship (Bilgin & Kucuk, 2010). The divorce rate of parents of children with ASD was 23.5%, which is significantly higher than that o of parents of typically developing children, at 13.81% (Hartley et al., 2010).

Parents of children with ASD also reported to experience stigma and discrimination as a result of challenging behaviour presented by their child (Buron & Wolfberg, 2014; Divan et al., 2012; Eaton, Ohan, Stritzke, & Corrigan, 2018; Gray, 1993; H. Hall & Graff, 2010; Nelson, 2002; Zhou, Wang, & Yi, 2018). In a study conducted by Gray (1993), 32 parents of children with ASD in Queensland, Australia, were interviewed to investigate their perception of stigma in raising a child with ASD. Parents in this study (Gray, 1993) reported to experience stigma they perceived as linked to their child's autistic characteristics such as disruptive behaviours, different physical appearance and social understanding. The finding from the study by Gray (1993) is consistent with the results of two other studies by Zhou et al. (2018) based in China and Eaton et al. (2018) undertaken in Australia. Large sample sizes were used with Zhou et al. (2018) being 263 participants and Eaton et al. (2018) being 424 participants, both reported on experiences of stigma in parents of children with ASD. Eaton et al. (2018) and Zhou et al. (2018) found a reported prevalence of discrimination among these samples, subsequently resulting in their isolation from the community.

A growing body of research on the impacts of ASD and challenging behaviour on the family has been undertaken in English speaking countries (Samadi & McConkey, 2014). Unfortunately, there are limited studies of this nature in Vietnam (Motchan, 2012; Vu et al., 2014) and no study about parents' experiences focussed on Quang Binh province. One of the few studies focussed on Vietnam was conducted by Motchan (2012), who provided a research report on the implications of living with ASD for children and their families. Motchan (2012) reviewed relevant studies, undertook observations in clinical and educational settings, interviewed relevant professionals, and engaged in surveys and interviews with parents of children with ASD in Ho Chi Minh City. Parents in Motchan (2012) study reported that they did not feel ashamed for having a child with ASD and they "still feel a great deal of love" (p.29). However, these parents reported significant levels of stress, financial burden and discrimination, which is supported by a study by Vu et al. (2014). Studies by Motchan (2012) and Vu et al. (2014) were very emerging research projects on ASD and its impacts on the family in Vietnam, providing an impetus to researchers and professionals and calling for great attention to this issue from the wider community. However, their samples were based in Ho Chi Minh and Hanoi cities, both urban contexts with higher standards of living and advanced social and economic conditions. Thus, these findings may not apply to Quang Binh, a small province in the centre of Vietnam with large number of people living in disadvantaged conditions.

2.5 Behaviour support strategies used by parents

Behaviour support strategies are used by parents in order to increase their child's desired behaviours and decrease their challenging behaviours (O'Nions, Happé, Evers, Boonen, & Noens, 2018). These may include, but are not limited to: (i) accommodating the child (Bagatell, 2016); (ii) modifying the environment (LeCuyer, 2014); (iii) providing structure and routines (Larson, 2006); (iv) using positive reinforcement (Gottuso, 2016); (v) supervising and monitoring (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011); (vi) distraction and diversion (Bagatell, 2016) and (vii) punishment (LeCuyer, 2014; O'Nions et al., 2018). These strategies are briefly discussed as follows.

2.5.1 Accommodating the child

Accommodations are adjustments intentionally made by parents to sustain family routines (Bernheimer & Weisner, 2007). This approach is often used by parents to manage challenging behaviours presented by their children with ASD (Ausderau & Juarez, 2013; Bagatell, 2016; Marquenie, Rodger, Mangohig, & Cronin, 2011). This can be done by accepting their child's preferences for sameness (Bagatell, 2016), adjusting family routines and strictly following the orders of actions to be done (Marquenie et al., 2011). Additionally, parents accommodated their child by avoiding things that their child dislikes and planning activities to reduce the likelihood of occurrence of potential challenging behaviours (Fletcher, Markoulakis, & Bryden, 2012). Further, adjusting behaviour goals to be achievable, giving extra time for task completion, and reducing demands when their child exhibits challenging behaviours were also helpful to address the child's challenging behaviours as reported by parents in studies by Bagatell (2016), DeGrace (2004), Divan et al. (2012), Marquenie et al. (2011) and Safe et al. (2012).

For example, Bagatell (2016) conducted a study with five families living with an adolescent with ASD in America to explore their experiences in constructing and managing their family daily occupations and routines. Using descriptive qualitative approach with semi-structured interviews and observations, all families in the study of Bagatell (2016) reported that 'somehow we make it work – most of the time' (p.54). Although the Bagatell (2016) study sample size was limited to five families, the results are consistent with previous studies, such as, Fletcher et al. (2012) and Marquenie et al. (2011).

2.5.2 Modifying the environment

Environmental modification is a strategy used by parents in order to increase the quality of life of the child, and as a result, address challenging behaviours (Boutot, 2017; LeCuyer, 2014; O'Nions et al., 2018; Richman, 2001). Modifying the environment is related to ensuring it is meaningful to the individual and potenitally reducing triggers (Boutot, 2017; Gottuso, 2016; Richman, 2001). A large quantitative study conducted by LeCuyer (2014) with 116 participants (50 African American and 66 European American mothers) examined their use of limit-setting behaviours and patterns with their children of

three years old. Research has suggested this approach to be associated with more positive behaviours in children. This finding is in line with a meta-analysis review by O'Nions et al. (2018) indicating that in order to manage challenging behaviours in children with ASD, parents commonly avoid using noisy appliances when the child is present, limit situations that are over-stimulating for their child and try not to take their child to new or different environments.

It is also important to acknowledge that some approaches that modify the environment may be restrictive practices. In the current Australian context, restrictive practices are any practice, device or action that restrict the individual's freedom, movement and abiity to make decisions (Government of South Australia, 2017). These include chemical restraint, detention, environmental restraint, mechanical restraint, physical restraint and seclusion (Government of South Australia, 2017). In the context of challenging behaviour, the environmental modification may include locking doors or other security devices to prevent the child leaving the house unnoticed, limiting the child to access valued things and potentially dengrous items such as sharp objects (DeGrace, 2004; Myers, Mackintosh, & Goin-Kochel, 2009). Although these approaches may be necessary to maintain safety of the child, they may also impact on the child's skill development due to his or her disengagement in a diverse range of social contexts, meaningful activities and opportunities (DeGrace, 2004; O'Nions et al., 2018). This suggests that changing the environment is not always a sustainable solution to manage challenging behaviours in children with ASD (Richman, 2001).

2.5.3 Providing structure and routines

Many studies reported that parents often adhere to fixed routines to reduce the likelihood of their child's challenging behaviour occurring (Duignan & Connell, 2015; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Larson, 2006; Schaaf et al., 2011). This was highlighted in a study conducted by Larson (2006), in which nine mothers who have a child with ASD were interviewed to examine the effectiveness of development and use of routines in their daily activities. Findings indicated that developing routines not only supported the child to be engaged in family activities but also created a liveable life for other family members. Findings from the study of Larson (2006) is also consistent with

research conducted by Kuhaneck et al. (2010) and Schaaf et al. (2011), in which researchers found that retaining sameness around daily activities at home assisted the child not to be exposed to unexpected stimuli, subsequently contributing to a reduction in challenging behaviour. However, some mothers reported that they experienced challenges in trying to balance and maintain sameness in their routines at the workplace and at home (Kuhaneck et al., 2010; Schaaf et al., 2011). Thus, further research could investigate skills that help parents of children with ASD and other family members develop effective routines for their child and family according to all family members' needs.

Many parents also provided structure and occupation to their child at all times to prevent potential challenging behaviours (Duignan & Connell, 2015; Fettig, Schultz, & Sreckovic, 2015; Johnson, Bekhet, Robinson, & Rodriguez, 2014; Scarpinato et al., 2010). This may include using visual aids such as pictures, checklists, video modelling or social stories to inform the child in advance what is happening next and their unpredictability and unexpected stimuli which can be difficult for individuals with ASD to process (O'Nions et al., 2018). Parents from studies of Ludlow et al. (2012), Duignan and Connell (2015) and Johnson et al. (2014) perceived that advance notices facilitated their child to transition smoothly from one activity to another, reduced anxiety in non-routine circumstances and supported reduced anxiety around acceptance of new experiences.

2.5.4 Positive reinforcement

Positive reinforcement is another strategy commonly used by parents to increase desired behaviours presented by their child (Gottuso, 2016; Payne & Dozier, 2013; Richman, 2001; Vong, Wilson, McAllister, & Lincoln, 2010; Williams et al., 2010). Positive reinforcement involves reinforcing (or 'rewarding') desired behaviours to increase the likelihood of these behaviours occurring again in the future. (Cooper, Heron, & Heward, 2007). According to Williams et al. (2010) and McEachern et al. (2012), parents reinforcing their child's positive behaviours reported a less occurrence of challenging behaviours in their child.

Consistent with the above studies, Gottuso (2016) researched behavioural strategies that were implemented by 56 parents of children with and without developmental disabilities

in New York, United States. In the Gottuso (2016) study, parents were asked to complete the Early Childhood Behaviour Screen (Holtz & Fox, 2012) to assess their child's behaviours and the Parenting Young Children: Self-Report Parenting Measure (McEachern et al., 2012) to evaluate their frequency of supporting positive behaviours to their child. Data analysis revealed that the more usage of positive reinforcement in parents, the lower level of occurrence of problematic behaviours in children with developmental disabilities (Gottuso, 2016). However, interpreting results from the study by Gottuso (2016) should be cautious due to its limitations. For example, data were analysed from 56 respondents of expected 226 parents (only 25%) and only 19 children were identified as having a developmental disability or delay. Consequently, the sample could not be representatives of the general parents.

2.5.5 Supervising and monitoring

Many studies have found that parents always need to supervise and monitor their child (Larson, 2010; Myers et al., 2009; Schaaf et al., 2011; Woodgate et al., 2008). Supervising and monitoring were essential for parents in providing behaviour support to their child by applying timely interventions (Schaaf et al., 2011). Supervision could also help parents reduce potential risks, particularly in uncertain circumstances such as in public places (Hodgetts, Savage, & McConnell, 2013). Finally, parents' supervising and monitoring were particularly important in everyday routines to ensure timely compensation for their child's difficulties in task performance (Larson, 2010).

Schaaf et al. (2011) conducted a qualitative study in the US to investigate the lived experiences of families having a child with ASD, focussing on impacts of challenging behaviours on family routines and roles. The Schaaf et al. (2011) study employed phenomenological design with in-depth interviews with four primary caregivers of children with ASD aged from 5 to 12 and challenging behaviours. Constant supervising and monitoring were strategies used by all parents in order to manage their child's behaviours and family routines (Schaaf et al., 2011). Findings from the study of Schaaf et al. (2011) is consistent with other studies such as Larson (2010), Myers et al. (2009) and Zhou and Yi (2014).

2.5.6 Distraction and diversion

Distracting the child is one of the strategies that parents used to manage and support their child with ASD (O'Nions et al., 2018). Many studies found that parents distracted their child to divert them from challenging behaviours and prevent outbursts in potentially challenging situations (Fettig et al., 2015; Sears, Blair, Iovannone, & Crosland, 2013). This can be done by using specific items e.g., phones, tablets and other technological devices (Bagatell, 2016) or giving their child a task such as pushing a trolley when shopping (Schaaf et al., 2011).

2.5.7 Punishment

It is important to note that in behavioural terminology, 'punishment' refers to approaches that decrease the likelihood of a behaviour – this may be as a result of applying an aversive consequence (e.g. yelling at child for inappropriate social behaviour - known as 'positive punishment'), or removing the 'payoff' for a behaviour (e.g., removing a favourite toy that children are fighting over – known as 'negative punishment') (Borgmeier & Rodriguez, 2015).

'Positive punishment' strategies (including verbal and physical) have been reported to be used by parents to manage challenging behaviours presented by their child (Armstrong & Kimonis, 2013; Hebert, 2014; Nicholson, Fox, & Johnson, 2005; O'Nions et al., 2018). For example, in a meta-synthesis to investigate parents' experiences in managing irritability, non-compliance, challenging behaviour and anxiety in their children with ASD (O'Nions et al., 2018), it was revealed that parents often used punishment approaches such as shouting, yelling and reprimands as a response to the child's challenging behaviours, which is consistent with a study by Bailey and Blair (2015). Parents of children with ASD also reported using 'negative' punishment' to reduce their child's challenging behaviours. For example, the child was grounded for misbehaivour or the child's favourite toy was taken away for fighiting with his siblings (Armstrong & Kimonis, 2013; O'Nions et al., 2018).

It is critical to note that punishment approaches may teach the child that specific behaviour is not acceptable; however, punishment does not always bring positive

outcomes. For example, Armstrong and Kimonis (2013) reported that '*restricting privileges created more problems than they solved'* (p. 63.) and Armstrong, DeLoatche, Preece, and Agazzi (2015) found that '*spanking and other forms of punishment such as removing items or privileges, had little effect on [the child's] behaviour*' (p.7). Indeed, punishment approaches focus on the reduction of challenging behaviour, but do not focus on increasing desired behaviours that will increase the individuals' quality of life.

2.6 Parents' support needs

2.6.1 Informal support

Informal support refers to any assistance or resource that comes from individuals who are not primary caregivers of the child such as family members and friends (Cooley, Thompson, & Newell, 2018; Searing, Graham, & Grainger, 2015; Shin & Lee, 2011). Previous literature suggests that the level of availability and helpfulness of informal support varies. Some parents of children with ASD and challenging behaviours reported receiving great assistance from their family and friends (Cooley et al., 2018; McConkey, Gent, & Scowcroft, 2013; Samadi, McConkey, & Kelly, 2012; Zuna, Gràcia, Haring, & Aguilar, 2016). This was emphasised in a study by Searing et al. (2015), which evaluated the support needs of families who have a child with ASD in New Zealand. Searing et al. (2015) used mix method design giving opportunities for participants to complete an online survey and express their perspectives for an optional free-text question. The Family Support Scale (Dunst, 1984) consisting of 18 self-report items was employed to rate the availability and usefulness of supports by caregivers in the last six months at the time of research. 82% of caregivers reported the most available and helpful informal support was from their partner/spouse (Searing et al., 2015). Other studies also investigated the informal support for parents, reporting that this source of support could come from children's grandparents (Divan et al., 2012), friends (Johan, Marijke, & Femke, 2015) and parents experiencing the same situation (Metcalfe & Sanders, 2012).

Lack of informal support, however, was also revealed in previous studies, with this resulting in significant stress for parents (Samadi et al., 2012; Searing et al., 2015; Zuna et al., 2016). For example, some parents expressed their feelings of bitterness as a result

of not receiving support and understanding from their family (Searing et al., 2015), which is consistent with studies by Bromley, Hare, Davison, and Emerson (2004) and Samadi et al. (2012). Bromley et al., (2004) interviewed 68 mothers of children with ASD to explore their psychological wellbeing status and satisfaction with supports. The researchers found that more than 50% of mothers experienced a low level of family support in caring for a child with profound challenging behaviours, subsequently leading to a lower level of wellbeing among parents (Bromley et al., 2004). Parents of children with ASD in another study by Samadi et al. (2012) also reported that they lacked or had no informal support from family, as one mother stated:

> *Generally, we receive no informal support. Our family tells us that there is no point in spending your time and money for your daughter. She is mad! Just one or two times they have helped (Samadi et al., 2012, p. 1448)*

As mentioned, challenging behaviours are associated with parents' stress, anxiety and depression (Divan et al., 2012; Motchan, 2012; Salari, Wells, & Sarkadi, 2014). Although informal support is not directly linked to a reduction in the child's challenging behaviours, it is a greatly valuable source of help for parents to provide them with the support needed to increase the higher quality of care for their children. However, previous studies reveal that there is still limited evidence to support positive outcomes of informal support for parents of children with ASD and challenging behaviours.

2.6.2 Formal support

Formal support refers to services provided by public and private organizations with fees, which may include family doctors, intervention training and respite care (Lindblad, Rasmussen, & Sandman, 2005; Shin & Lee, 2011). Parents of children with ASD and challenging behaviours may rely on formal support for information and intervention programs, which may relate to parenting training and education on behavioural problems and interventions, empathy and understanding of family potential challenges (Lindblad et al., 2005). Like informal support, there is a mixed perception of parents regarding the availability and helpfulness of services that they received from professionals.

In a quantitative study using questionnaires, McGill, Papachristoforou, and Cooper (2006) aimed to understand the nature of and satisfaction with support services that family carers of children and young people with developmental disabilities and challenging behaviour received from professionals. Questionnaires focussing on behaviour support services were divided into medication, psychological advice/treatment, communication advice/treatment and other advice/treatment (e.g. parent training, equipment, or adaptation), and respite care (McGill et al., 2006). Among 66 participants, more than 50% reported that they did not receive professional services and service provision was not helpful. Further, nearly 70% of caregivers reported experiencing respite care services; however, of these, a third reported that their child was excluded for reasons including challenging behaviour (McGill et al., 2006). Overall, McGill et al. (2006) found that families of children with challenging behaviours received little support from professionals, and behaviour support services provided were almost unhelpful for them.

Support services for families of children with challenging behaviours were also investigated in qualitative papers (McConkey et al., 2013; Searing et al., 2015; Wodehouse & McGill, 2009). In the UK, Wodehouse and McGill (2009) employed interpretative phenomenological method to interview 13 mothers who had a child with challenging behaviours to examine their perceptions of support services for their child. Many mothers reported receiving behaviour support services from psychologists, nurse specialists, challenging behaviour 'teams' and mental health services. However, many problems regarding service provision were significantly highlighted in the Wodehouse and McGill (2009) study. Many mothers reported challenges in accessing specialist services due to their availability. Additionally, most mothers viewed challenging behaviour-specific support services as ineffective because professionals lacked expertise in the challenging behaviour area and suggested interventions were not evidence-based. Parents also expressed that they need more training in order to provide behaviour support to their child at home (Wodehouse & McGill, 2009). Findings from Wodehouse and McGill (2009) are consistent with the above quantitative study (McGill et al., 2006) and other qualitative studies such as McConkey et al. (2013) and Searing et al. (2015).

Previous literature indicated that parents of children who have ASD and display challenging behaviours receive training in the use of positive behaviour support strategies are able to reduce the occurrence of their child's challenging behaviours (Bearss, Johnson, Smith, & et al., 2015; Chai & Lieberman-Betz, 2018; Gore & Umizawa, 2011; Preece, 2014; Sellinger & Elder, 2016). Preece (2014) investigated the impact of a training model in positive behaviour support and physical interventions for families of children with ASD and challenging behaviours. Two six-hour training sessions were provided for a total of 11 parents, followed by a 12-week period of follow-up sessions with local trainers (Preece, 2014). The training covered positive behaviour contents including the definition of challenging behaviours; ways of communication and de-escalation of challenging behaviours; rights and responsibilities and the use of physical interventions and contextual modification (Preece, 2014). Parents were also instructed how to respond to specific challenging behaviours such as biting and hair-pulling. Data were collected by questionnaires, surveying parents before and after the training and after the 12-week follow-up sessions, via semi-structured interviews. Overall, parents reported to increase their understanding of challenging behaviours and their confidence in the use of behaviour support strategies immediately after the training and over the follow-up period. This subsequently leads to a significant reduction in their child's problematic behaviours (Preece, 2014). Findings from Preece (2014) suggested that providing training to families of children with ASD and challenging behaviours could produce positive outcomes to both parents and children in the reduction of challenging behaviours, which is strongly in line with other research conducted by Gore and Umizawa (2011) and Bearss et al. (2015). Unfortunately, positive behaviour support training is rarely provided to parents and other family members in Vietnam.

In Vietnam, there are limited supports available to parents of children with ASD and in particular those living with challenging behaviours. First, ASD diagnosis and treatment services are only available in National Hospitals in urban cities such as Hanoi, Ho Chi Minh, Hue and Danang, where the processes are reported to be long and expensive (Motchan, 2012; Vinahealth, n,d; Vu et al., 2017). Therefore, families living in rural areas may have difficulties accessing these services (Vinahealth, n,d). Secondly, there are no policies specific for children with ASD and their family in Vietnam. Current policies that

support these groups are mentioned in policies for children and people with disabilities (Vinahealth, n,d). According to the National Law on People with Disabilities (National Assembly of Vietnam, 2010), only families of people with profound disability are eligible to receive a monthly subsidy of about 270,000 Vietnam Dong (AUD17). However, ASD is not categorised as a specific type of disability in this law (National Assembly of Vietnam, 2010), meaning that parents of children with ASD struggle to get a disability diagnosis and receive a certificate of disability for their children. Without this certification, children with ASD and their parents could not receive subsidy from the government. The Vietnam Autism Network (VAN), was recently established in 2013 by Department of Labour, Invalid and Social Affairs, Vietnam Federation of People with Disabilities and Asia-Pacific Development Centre on Disability- APCD. VAN is an organization of parents with ASD and anyone interested in ASD in Vietnam (VAN, n.d). VAN provides training to build capacities for people with ASD and their families (VAN, n.d). However, parents from only six provinces excluding Quang Binh are currently involved in this organization and VAN services are also based in Hanoi.

2.7 Summary

A review of current research relating to ASD and challenging behaviours was presented in this chapter. It highlights the complexity of ASD and resulting challenging behaviours and the significant impact on the child and families. Strategies that parents often utilised to manage their child's behaviours included (i) accommodating the child, (ii) modifying the environment, (iii) providing structure and routines, (iv) using positive reinforcement, (v) supervising and monitoring, (vi) distraction and diversion and (vii) punishment. This review also highlighted family needs relating to behaviour supports that facilitates the development and inclusion of children with ASD. Challenging behaviours in children with ASD and parents' experiences in behaviour support in the Vietnamese context were discussed and research gaps were highlighted. The following chapter will outline the research methodology used to collect and analyse data.

CHAPTER 3
METHODOLOGY

3.1 Introduction

This chapter presents the methods utilised in addressing the research objectives. It first provides an overview of the phenomenological approach, followed by a description of the process of recruiting participants, collecting data and analysing data. The ecological systems theoretical framework is also presented, which was used as the framework to present and discuss findings. Considerations are given to epistemology and reflexivity, which is important to acknowledge the personal opinions and biases, and the researcher-participant relationship. Finally, ethical considerations will be presented.

3.2 Research design

A qualitative approach was selected to investigate the central phenomenon. It is an appropriate approach to research that aims to explore subjective views and lived experiences through sharing stories (Creswell, 2013a). Phenomenology is commonly used in qualitative research methodology (Creswell, 2013b; Saldana, 2011), which is based on a fundamental concept that the meaning of individuals' lived experiences is valuable and possible to identify (Crotty, 1998; Greene, 1978). The aim of phenomenological approaches is to gain insights into 'how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others' (Patton, 2002, p. 104). The central phenomenon of the current study is the experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam. Hence, it is best explored through a phenomenological approach.

Phenomenology consists of two approaches: descriptive and interpretive (Lopez & Willis, 2004; Touhy, Cooney, Dowling, Murphy, & Sixsmith, 2013). Descriptive phenomenology is stemmed from a philosophy that human experiences are critical to understand the world (Husserl, 1970). The aim of descriptive phenomenology is to describe general

characteristics of a phenomenon rather than human experiences to identify the phenomenon's meaning or essence (Touhy et al., 2013). Descriptive phenomenology requires the researcher to set aside time, place and all existing knowledge about the phenomenon to capture its universal essence in pure forms (Matua & Van Der Wal, 2015; Touhy et al., 2013). Interpretative phenomenology, on the other hand, is based on an idea that phenomenological inquiry should stress on the relation between individuals and the world they live in (Heidegger, 1962). The aims of the interpretative phenomenology are to describe, understand and interpret the meaning of the lived experiences of individuals in various contexts (Matua & Van Der Wal, 2015; Touhy et al., 2013). Although the descriptive phenomenology describes 'a pure description of lived experiences' (Van Manen, 2016, p. 25), it is rarely perfectly obtained (Creswell, 2013a; Van Manen, 2016). Thus, this study adopted the interpretative phenomenological approach as it allows the researcher to describe and interpret the lived experiences of participants through her perspectives which is implemented through the process of data collection and analysis.

In order to carry out a phenomenological research, the researcher collects information from participants who have lived experiences with the phenomenon (Creswell, 2013a). All aspects of the participants' experiences will then be explained comprehensively including what and how they experience the central phenomenon (Creswell, 2013a). Data are mainly collected by in-depth interviews with participants (Creswell, 2013a). Data are analysed by a structed process commencing from narrow analysis to wider analysis and then to a detailed explanation (Creswell, 2013a). Finally, a detailed description of what and how participants experience the phenomenon is produced (Creswell, 2013a).

3.3 Participant recruitment

Inclusion criteria for participation in this study required that parents:

- were above 18 years old and were living in Quang Binh Province
- had a child diagnosed with autism under 18 years old, and
- were able to communicate via email, Skype or Facebook

Purposeful sampling was selected to identify research participants. This strategy is commonly used in qualitative research and refers to participants who have lived experiences of the phenomenon being examined (Creswell, 2013b). For the purpose of this study, parents who have lived experiences in providing behaviour support to children with ASD in Quang Binh, Vietnam were recruited to address the research questions.

The researcher contacted the Association for Empowerment of Persons with Disabilities (AEPD) and Dong Hoi Centre for Caring and Educating Children with Disabilities (Dong Hoi Centre) via email with details of the study (including a letter of introduction [Appendix A] and information sheet [Appendix B]) to seek assistance with recruitment. AEPD is a non-profit organization working in the disability field in Quang Binh Province and Dong Hoi Centre is a state organization providing caring and educating services for children with a variety of disabilities in Dong Hoi City, Quang Binh Province.

Key contacts from AEPD and Dong Hoi Centre then disseminated information about the study to potential participants. This included a letter of introduction (Appendix A), information sheet (Appendix B) and consent form and contact details for participation in research (Appendix C). Potential participants who were interested in this study and met inclusion criteria were asked to contact the researcher directly to register their interest. The researcher then contacted them via Facebook inbox and email to forward the study documents, providing them with the opportunity to ask questions before signing consent.

The first ten parents to register their interest and who met inclusion criteria were recruited for this research. A sample of 10 participants was deemed appropriate given the scope of this Master dissertation, and it has been suggested that between six and ten participants is sufficient in phenomenological studies (Creswell, 2013b).

3.4 Data collection

Data were collected through semi-structured interviews, which is a common form of data collection in qualitative research (Creswell, 2013b, 2014; Gray, 2004). Semi-structured interviews are ‘a set of predetermined open-ended questions, with other questions emerging from the dialogue between interviewer and interviewee/s’ (DiCicco-Bloom &

Crabtree, 2006, p. 315). The semi-structured interviews allow the researcher to discover the lived experiences of participants in their own words by creating a flexible space for them to tell their stories (Kvale & Brinkmann, 2009). The interview process and questions are outlined in Appendix D. The interview questions were designed to address the research questions regarding (i) strengths and challenges experienced by parents in providing behaviour support to children with ASD in Quang Binh, Vietnam, and (ii) support services that parents were receiving and their needs specific to providing behaviour support. All interview questions were translated into Vietnamese, with interviews conducted in Vietnamese as it was the native language of the participants and the researcher.

The researcher carried out all interviews with participants in a private meeting room at Flinders University to ensure privacy and confidentiality. Each interview lasted approximately 45 to 60 minutes and was conducted via Facebook or telephone according to the participants' preference and convenience. Prior to each interview, the researcher introduced herself and briefly summarized the aims of the study and participant involvement. The researcher also made sure that participants clearly understood that their participation was voluntary, and they were free to discontinue participation or refuse to answer any questions. The researcher commenced the interview by asking questions about the demographics of the participants and their child.

During the interview process, interviews were audio recorded with permission from the participants and stored on a password-protected computer. Note-taking was also employed, helping the researcher to formulate additional questions and probes and take reflective notes that could facilitate further data analysis (Patton, 2002). All participants were given the opportunity to add any further information or have any questions to the researcher at the end of the interview. Each participant was sent a copy of their interview transcript in Vietnamese shortly after their interview, giving them an opportunity to review and edit information presented.

As part of maintaining the integrity of the research process, transcripts of recordings provide an excellent record of natural interactions between the researcher and

participants (Seale & Silverman, 1997). Thus, recordings and transcripts are highly reliable sources of data that help the researchers return to cross-check in the process of data analysis

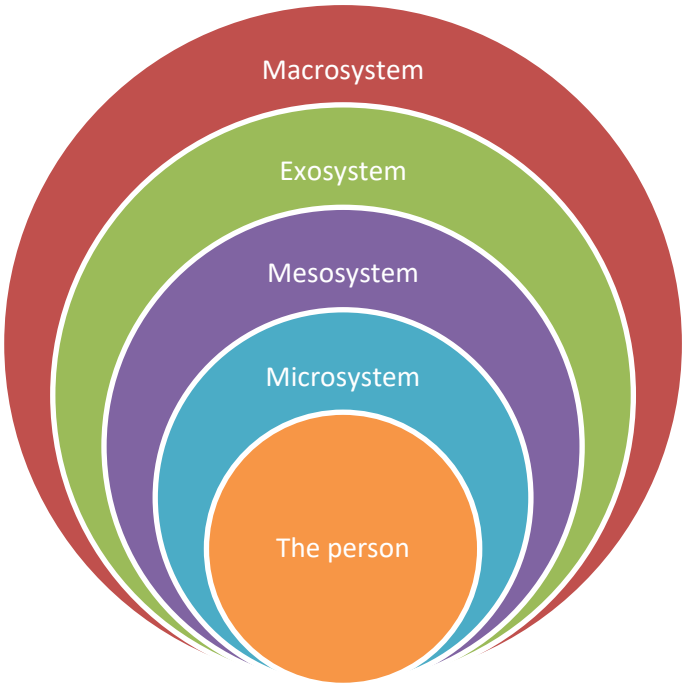
3.5 Theoretical framework

A theoretical framework provides a lens which the researcher could understand and present the phenomena (Anfara, 2008). In qualitative studies, theoretical frameworks are useful, as they not only give meanings to the research findings, but also link these findings into a coherent structure (Polit & Tatano, 2004). It is believed that the study results are more easy to understand through relevant theoretical frameworks (Polit & Tatano, 2004).

Understanding the lived experiences of an individual should be placed within social and cultural contexts in which the individual is living (Creswell, 2013a). For parents of children with ASD, their experiences in behaviour support to their child with ASD are likely to be influenced by their relationships with their child, their family, culture and dynamics, service providers and communities in which they live and interact directly or indirectly. Thus, for the purpose of this study, the ecological systems theory (Bronfenbrenner, 1977, 1989) was adopted as a theoretical framework to guide and interpret the research findings. This theory helps the researcher conceptualise what and how parents experience behaviour support to their child with ASD at differently levels in which they have direct and indirect interactions.

The ecological systems theory was developed by Bronfenbrenner (1979) as a 'scientific study of the progressive, mutual accommodation between the developing person and the changing properties of the immediate and broader contexts in which the person lives' (p.21). According to Bronfenbrenner (1979), each person's ecological systems are divided into four different systems: microsystem, mesosystem, exosystem and macrosystem. These systems are illustrated in Figure 3.1.

Figure 3.1: The ecological systems theory



The microsystem is the immediate system of environment consisting of activities and the relationships that the person interacts and experiences with his/her immediate surroundings (Bronfenbrenner, 1979). For parents of children with ASD, this layer may include parents, their worldview, their child, and their immediate family.

The mesosystem is the link between settings of the person's microsystems (Bronfenbrenner, 1979). This system allows the researcher to explore the relationship between parents of children with ASD and their extended families, friends, colleagues and their support networks.

The exosystem is a social system that does not impact the person directly. However, it consists of events occurring within the immediate setting (microsystem) that indirectly impacts on the person (Bronfenbrenner, 1979). For parents of children with ASD, this system may contain the local and national policies regarding children with ASD and their families.

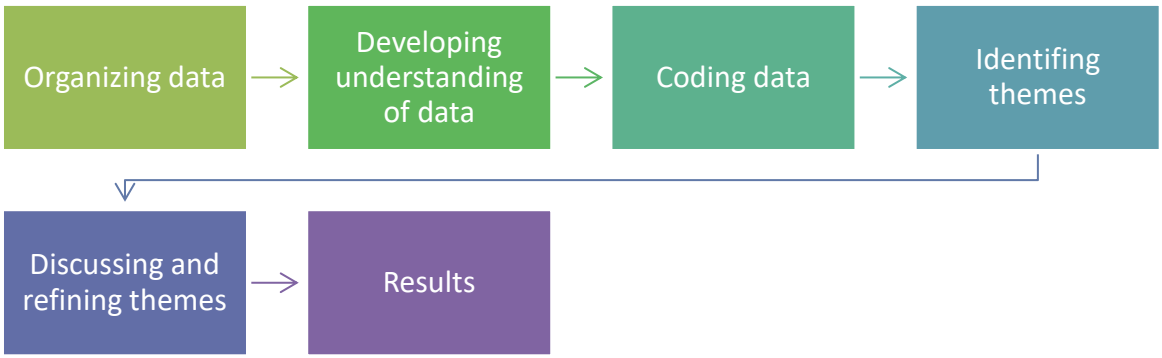
The macrosystem contains larger social principles including cultural values and beliefs (Bronfenbrenner, 1979). These broader cultural views have an impact on each of the system later. The beliefs and cultural values could affect parents' experiences in accessing support services for their child as well as supporting their child in public places.

Using this systems lens to interpret the current research findings allowed the researcher to gain preliminary insights into how these systems may influence the parents' experiences in providing behaviour support to their children with ASD in Quang Binh, Vietnam

3.6 Data analysis

Data analysis is a process of analysing and interpreting research data (Creswell, 2017). Of approaches to analyse data in phenomenological research, the interpretative phenomenological analysis (IPA) presented by Larkin and Thompson (2012) allows the researcher to analyse data collected from participants with detailed experiences. The IPA consists of different steps including identifying 'themes' that are drawn from the detailed, line-by-line commentary on the data, called 'codes' (Larkin & Thompson, 2012, p. 105). These themes are then presented in a structure with a narrative explanation. For the purpose of this study, the IPA was selected to analyse and interpret data collected from interviews with research participants (Larkin & Thompson, 2012). The steps of analysing data in the current study (Figure 3.2) were adapted from Larkin and Thompson (2012) and Creswell (2017a) and are described below.

Figure 3.2 Steps of data analysis



Step 1: Organising data: The data organisation is important in qualitative study due to the large amount of information gathered during the study (Creswell, 2014). At this point, the researcher transcribed all interview recordings into texts and organized them by the participant name (Creswell, 2014). All participants were de-identified to ensure confidentiality.

Sept 2: Developing understanding of data: the researcher read the interview transcripts several times to develop a deeper understanding of information provided and identify codes. Additionally, a second reviewer also reviewed de-identified interview transcripts.

Step 3: Coding: all texts were imported into NVivo 11. NVivo is a computer software for qualitative data analysis developed by QSR International Pty Ltd (2018). It provides a toolkit for coding themes and conducting analysis, enabling the researcher to compare data by creating text data matrixes and visual mapping categories in the study (Creswell, 2017a).

Inductive coding was applied to draw meaning from text data developed from interview recordings. Inductive coding is an approach that allows research findings to appear from 'the frequent, dominant or significant themes inherent in raw data' (Thomas, 2006, p. 238). At this stage, the researcher performed line-by-line analysis of the transcripts to produce codes. The researcher and primary supervisor then discussed the codes identified to reach consensus on code names and sort the codes into themes (Nowell, Norris, White, & Moules, 2017). Only codes related to research questions were included.

Step 4: Identifying themes: the researcher categorised similar codes into themes with names while redundant codes were deleted (Creswell, 2017b).

Step 5: Discussing and refining themes: quotes and themes were translated into English for the supervision team to read and review. The researcher met with the two supervisors to discuss the coded data and refined themes, which helped check and improve the consistency and credibility of the data interpretation.

Step 6: The results: the researcher wrote a narrative report to present the results. The process of data analysis and interpretation were reviewed and discussed with the

researcher's two supervisors who have extensive experience and expertise in the content area and method utilised.

The research findings were placed within their corresponding systems within the ecological systems theory, which represents parents' interaction between their self- and surrounding contexts. This helped explore how parents' ecological systems impact their experiences in providing behaviour support to their child with ASD.

3.7 Epistemology

Epistemology refers to the way of understanding and explaining 'how we know what we know' (Crotty, 1998, p. 8). Epistemology in qualitative research questions the relationships between the researcher and the phenomenon (the object) being studied, and between the researcher and participants experiencing this phenomenon (Miller, 2013). Reflexivity is one of the fundamental epistemological considerations in qualitative research, referring to a process in which the researcher takes his/her personal opinions into consideration and critically evaluates how these may impact the research process and outcomes (Berger, 2015).

It is therefore important to acknowledge that the researcher has experiences working with parents of children with ASD in Quang Binh. As a result of her interactions with and observations of parents and their children, she believes that effective behaviour support is crucial in promoting meaningful outcomes for children. She also felt that family members were not well supported in providing this support to their child.

In spite of possible presence of personal opinions, the researcher is recommended to approach the topic with openness (Finlay, 2014). Thus, strategies were used to maintain the reflexivity of this study. These included recruitment of participants from different backgrounds, use of open-ended interview questions, audio recordings of interviews to provide contextual pauses and in participant responses, member checking after interviews, note-taking during interviews, an independent member of the research team in analysing data, and data analysis and interpretation checked by supervisors with relevant expertise (Creswell, 2017a; Ramani, Könings, & Mann, 2018).

3.8 Ethical consideration

Ethical issues were taken into careful considerations when conducting this research (Creswell, 2017a). Ethics approval was obtained from Flinders University Social and Behavioural Research Ethics Committee (SBREC; project number: 8180 [Appendix E]). Consent for participation was obtained from participants before conducting and recording interviews. All data were de-identified and stored on a password-protected computer. Participant information remained confidential and was only viewed by the researcher and supervisors.

It is acknowledged that there were potential risks of psychological distress participants may experience during the interview due to the nature of this study. The researcher provided participants with contacts of Counselling, Research and Life Psychology JSC, Viet Nam – a counselling service in the information sheet. The researcher also reminded the participants that they are free to refuse to answer any questions and withdraw from the interview at any time without effect or consequences.

3.9 Summary

This chapter described the phenomenological research methodology utilized in this study. This was selected in order to gain insights into the lived experiences of people. Semi-structured interviews were conducted with ten parents recruited through AEPD and Dong Hoi Centre in Vietnam. During the interviews, participants were asked questions relating to their strengths, challenges and support needs in providing behaviour support to their child. The data was then transcribed and analysed using thematic analysis. The ecological systems theory was also introduced as a framework to understand how participants' experiences were impacted by their ecological systems. The researcher' personal opinions were also presented, with epistemology and reflexivity important to acknowledge when conducting research. Finally, ethical considerations including informed consent, confidentiality of data and concerns of psychological distress were addressed.

CHAPTER 4
RESULTS

4.1 Introduction

This chapter presents the findings from the semi-structured interviews with ten parents of children with ASD. Demographic characteristics of participants will be presented, followed by the major themes that emerged from participants' responses. Strengths, challenges, current support and support needs of parents in providing behaviour support to their child will be presented below.

4.2 Demographic characteristics of participants

A total of ten participants (nine mothers and one father) returned signed consent forms and were invited to participate in this study. Their age varied from 28 to 52. The vast majority of parents (eight) were married and living with their family, inclusive of their child with ASD. Seven out of ten parents were living in rural areas, and at the time of the study, eight parents were working, and two mothers were staying at home to take care of their children. All participant names were changed.

Nine of the ten children in this study received a formal diagnosis of ASD, and of these children, seven were boys and six were the second child in their family. Children age ranged from four to twelve. All ten children exhibited a variety of challenging behaviours, including crying, screaming, self-harm, physical aggression towards others, property destruction, repetitive activities, special interests, and toilet incontinence. Eight children were attending schools, with six at special schools and one at mainstream school. The demographic characteristics of participants and their children with ASD are summarised in Table 4.1.

Table 4.1. Demographic characteristics of participants and their children with ASD

Parents' information							**Child's information**				
Name	**Age**	**Role**	**Marital status**	**Living area**	**Numbers of children**	**Employment**	**Age**	**Gender**	**Age of ASD diagnosis**	**School attendance**	**Challenging behaviours**
Anh	47	Mother	Divorced	Rural	1	Casual	12	Male	2 years	No	Self-injury
Duc	49	Father	Married	Urban	3	Full-time	12	Male	2 years	Special school	Crying and screaming, toilet incontinence, property destruction
Hien	38	Mother	Divorced	Rural	2	Full-time	11	Male	1,5 years	Special school	Restricted interests (e.g. only liked playing with bottles), screaming, property destruction,

Parents' information							Child's information				
Name	**Age**	**Role**	**Marital status**	**Living area**	**Numbers of children**	**Employment**	**Age**	**Gender**	**Age of ASD diagnosis**	**School attendance**	**Challenging behaviours**
											absconding/running away, self-injury
Hong	29	Mother	Married	Rural	2	Unemployed	8	Male	4 years	Special school	Self-injury, property destruction, screaming,
Huong	40	Mother	Married	Rural	2	Full-time	6,5	Female	2 years	Special school	Restricted interests (e.g. Like playing with her dolls only), difficulties in communication with strangers
Lan	52	Mother	Married	Urban	3	Casual	8	Male	3 years	No	Self-injury, physical aggression towards

Parents' information							Child's information				
Name	**Age**	**Role**	**Marital status**	**Living area**	**Numbers of children**	**Employment**	**Age**	**Gender**	**Age of ASD diagnosis**	**School attendance**	**Challenging behaviours**
											others, leaving the house unnoticed
Mai	28	Mother	Married	Rural	2	Full-time	4	Female	2,5 years	Special school	Repetitive interest (e.g. putting her hands in her mouth all day)
Nga	37	Mother	Married	Urban	2	Full-time	4,5	Male	3 years	Mainstream school	Self-injury, physical aggression towards others, difficulties in communication, screaming, property destruction
Nhu	33	Mother	Married	Rural	2	Full-time	4,5	Male	Not diagnosed	Special school	Repetitive interests (e.g. playing alone), difficulties in

Parents' information							Child's information				
Name	**Age**	**Role**	**Marital status**	**Living area**	**Numbers of children**	**Employment**	**Age**	**Gender**	**Age of ASD diagnosis**	**School attendance**	**Challenging behaviours**
											communication, screaming
Thanh	40	Mother	Married	Rural	2	Unemployed	8	Female	3 months	No	Screaming, irritating, self-injury

4.3 Parents' strengths

4.3.1 Using preventative strategies

Parents in this study reported using different strategies to provide behaviour support to their children, including modifying the environment at home, increasing predictability of incoming events/places, distraction and punishment.

(i) Modifying the environment at home

Four parents reported that they had to modify their home environment to prevent their child's challenging behaviours. For example, Lan stated:

> *… my house was close to a big road and my child often ran out to the road when lots of vehicles were on their way. This was very dangerous. Thus, I always had to lock the gate so that he could not run out.*

Reducing access to household items was also illustrated in responses by two other parents as below.

> *At home, I must lock all wardrobes and cupboards. Otherwise, she would open and close them all day* (Mai).

> *Now, everything in our house must be locked or put in higher places where he could not reach. Because whenever he was overwhelmed, he could take anything and throw away. He did not care what it was. He threw whatever he saw* (Hong).

(ii) Increasing predictability of upcoming events/places

Three participants reported that they provided their child with cues of upcoming events/places as a way of behaviour support. Huong, a mother of a child with ASD aged six and a half stated:

> *I tried to talk more with her. Before bringing her to somewhere, I would talk to her about that place, what it would look like, who would be there, what activities would*

be, how to respond to people that might talk to her. Gradually, she seemed to be open in conversations with others.

Lan also concurred with Huong in using this strategy as reporting that she always utilised visual supports to tell her son where they were about to go, what they would do there and how they would engage with other people.

(iii) Distraction

Five parents in this study reported using different ways to respond to their child's challenging behaviours. Distracting the child when she/he presented challenging behaviours was a solution of some parents in this study, as reported by five parents. For example, Duc responded:

> *When [my child with ASD] wanted something and we did not give it to him, he would cry, cry loudly. At that time, I took him to somewhere or allow him to get in our car and he would stop crying.*

Mai also distracted her child to manage her challenging behaviours, reporting '*She would yell when she wanted something. Sometimes I gave it to her but sometimes I would take her to my motorbike and drove her somewhere. A moment later, she would forget it' (Mai).*

(iv) Punishment

As mentioned in Chapter 2, punishment strategies can be positive (adding an aversive consequence) or negative (removing a payoff). Over half of the participants reported using 'positive punishment', reporting that they always 'shouted at or hit' their child when they presented challenging behaviours at home. For example, Nga asserted '*Sometimes, I felt too stressed with his challenging behaviours, so I shouted at him or hit him on his hands or his bottom'.* This solution was also highlighted in responses from five other parents. One of the mothers who had a child with ASD aged four and a half reported '*She*

cried whenever her needs were not met timely. Sometimes, I used my hand or a stick to hit her hand or her bottom' (Nhu).

Two other parents reported using 'negative punishment' by ignoring the child when they presented challenging behaviours. *For example, Lan responded 'Sometimes, I did not know what to do with him, so I just ignored his tantrums and left him alone'.*

4.3.2 Responsibility and love for the child

Ten parents reported a sense of responsibility for their child, and unconditional love for their child. They all perceived that these factors are significantly important in providing effective behaviour support to their children with ASD.

For example, Nhu reported:

> *I was really sad. But I did not allow myself to have that feeling for long. She was my daughter. I gave her birth. Now I could not refuse her. I needed to find different ways to support her.*

Duc also expressed:

> *I knew that my child was different from other children. He sometimes made me stressed. But he was my son. I loved him for who he was. If I did not love him, we would not take him to different hospitals to find good doctors and apply good strategies to support him* (Duc).

4.4 Parents' challenges

Parents reported significant weaknesses in providing behaviour support to their children with ASD. These included (i) limited knowledge regarding ASD and behaviour support, (ii) financial barriers in accessing support services, (iii) limited time to attend training courses regarding behaviour support, and (iv) stigma and cultural attitude.

4.4.1 Limited knowledge regarding ASD and behaviour support

All ten parents in this study reported that they had limited knowledge regarding ASD, challenging behaviour and support strategies. For example, Hien stated:

> *My child [with ASD] had a lot of challenging behaviours. I really wanted to support him to improve these behaviours. Unfortunately, I had limited knowledge in this area such as what challenging behaviour was, what interventions were effective and how to apply these interventions to him at home* (Hen).

Nhu and Thanh also concurred with Hien as illustrated in their responses below.

> *In my living area, there were not so many children who had ASD and challenging behaviours like mine. So, I did not know much information about this disability and how to support her. Until now, what I knew was from the internet, but it was just for reference* (Nhu).

> *It seemed that my child was the only person with this disability in this commune. Further, I lived in a rural area where there was limited information about this disability. Thus, I did not know how to support my child* (Thanh).

4.4.2 Financial barriers in accessing behaviour support services

Finance was a significant issue reported by all ten participants in this study. Parents reported to experiencing financial burdens in assessing services for themselves that could help them in providing behaviour support to their child. For example, Hien stated:

> *At the moment, training courses on ASD, challenging behaviour and support strategies were only available in large cities such as Da Nang, Ha Noi and Ho Chi Minh City. However, the participation fee for these courses was quite high, about three million VND [Vietnam Dong] per course. You knew, three million VND was only for participation fee. I had to pay for others such as transportation, accommodation, etc. I really wanted to attend these courses so that I could support*

my child. But the costs were so high. 3 million VND was higher than my monthly salary.

Additionally, finance was also a barrier preventing parents from accessing services for their child. For example:

> *I knew that his challenging behaviour would be positively improved if he could attend school because teachers there had knowledge, skills and knew many interventions. However, the cost was so expensive. … his school fee was 3 million VND per month, and it was 5 million VND per month if he attended a full week from Monday to Sunday. Only parents who had stable and high income were able to send their children to schools. Poor families accepted to let their child stay at home* (Lan).

> *I used to send my child to service centres for behaviour support in Hanoi and Ho Chi Minh Cities. … The cost was so high. You knew Hanoi and Ho Chi Minh were too far from Quang Binh. In addition to costs for services at these centres, I had to pay for accommodation, transportation, clothes and many others. After several months, we must go back to Quang Binh because we could not endure such high expenses* (Duc).

4.4.3 Limited time to attend training regarding behaviour support

The majority of parents (n=7) reported that they experienced difficulties in arranging a time to attend training courses on challenging behaviour and support strategies. For example, a Huong stated:

> *You knew parents must also work. Both my husband and I were working for government organisations. We only had a short leave per year. Meanwhile, it took time and costs to attend training courses on challenging behaviour and related topics. Further, these courses were only in Hanoi and Ho Chi Minh City. Thus, I could not arrange a time to attend these courses* (Huong).

Duc also concurred with Huong's response as reporting that:

> *… services on ASD and behaviour support were only available in Hanoi and Ho Chi Minh City. I was a governmental officer. I could not have many days off to go to these cities to attend these courses. I also needed to work to earn money for my family*.

4.4.4 Stigma and cultural attitude

More than five parents reported experiencing stigma and discrimination towards their child due to the child's challenging behaviours. This led to social and educational exclusion of the child.

Nine out of ten parents responded that they had difficulties in enrolling their children with ASD in schools, especially mainstream schools. For instance, Hong reported:

> *I bought him to six mainstream schools to enrol for him. However, all these schools refused to accept my child. They said that my child often threw objects, harmed himself and others. They were afraid of being responsible for my child if something bad happened to him.*

This experience was also highlighted in Lan's response as below:

> *My child is now eight. He should go to primary school, in grade 2. However, no public schools accepted him. One centre for children with disabilities accepted him but my child could not still attend. This was because most of the students at this centre were with physical disabilities and they could communicate with educators. Meanwhile, my child could not speak, and no educators specialized in teaching students with ASD like my child. So, I just let him stay at home with my mum.*

Four parents also reported that the social inclusion of their children was impacted by their challenging behaviours. For example, Hien reported:

At present, with his challenging behaviours, I could not bring him to public places. I only drove him around parks or playgrounds. I could not stop at these places. If I stopped, he could take whatever he liked though that's not him. He did not know what actions were accepted and what not there. He just did what he liked. So, I could not almost allow him to play in public places.

This experience was also reported by three other parents, as bellow.

He liked playing with children living surrounding our house, but these children did not want to play with him because he often threw objects and harmed others (Hong).

I rarely brought her to public places because I was afraid that I could not control her behaviours (Thanh).

I rarely took her out of our house because I was afraid of people staring at her. Some parents even did not allow their children to play with her (Lan).

In addition to the community discrimination, one parent experienced stigma from her family as illustrated in her response 'My *parents-in-law was not aware of ASD related challenging behaviours. They thought that my child's behaviours were caused by our [parents] faults'* (Mai).

4.5 Parents' current support

Some parents reported that they were experiencing some behaviour support services. These included (i) professional support, (ii) social network and (iii) family support. However, parents' perception of helpfulness of the support varied.

4.5.1 Professional support

A majority of parents (n=7) reported receiving support from professionals, including general practitioners and educators. This was indicated in their responses as below.

Doctors at a hospital in Ho Chi Minh City where my son had received his diagnosis provided me with some knowledge of ASD, challenging behaviours. They also taught me some intervention strategies so that I could support my child at home (Anh).

Doctors said that my child had mild ASD so we ourselves could support her at home. They also shared with me some documents on ASD, challenging behaviours and instructed how to support my child at home (Huong).

Doctors explained to me what ASD was, what challenging behaviours my child might present and how to respond to these behaviours (Lan).

My child was attending a special school. Educators sometimes talked to parents to update our children' progress and shared new information about ASD (Hien).

4.5.2 Social network

Parents in this study also received support from the social network. Four parents reported that they received support from other parents what also had a child with ASD and presented challenging behaviours. For example, Lan responded:

I was participating in a group of parents of children with ASD. We often organised activities to share information about ASD and interventions. We also shared with each other good services for children with ASD with reasonable costs so that other parents could access for their child.

Another mother, Mai also reported gaining supports or experiences from other parents, stating *"I worked for a special school. I often met other parents whose children were attending here. Sometimes, we talked to each other about our child's improvement'.*

However, some parents (n=6) reported that support from social network was not available for them. For example, responses from Nhu and Thanh revealed that they were living in

a rural area where there were not many children with ASD like theirs, which resulted in limited social networks and support from families experiencing similar situations.

4.5.3 Family support

Only three parents reported receiving support from their family, as illustrated in their responses below.

> *We were living with my parents. Sometimes, they helped me to play with my son, so I could have some time for myself* (Hien).

> *Everyone in our family or extended family knew that he had ASD. He was the youngest child in our family. His two sisters loved and cared for him. They spent lots of time with him* (Lan).

Meanwhile, seven parents reported they did not receive any support from their family as illustrated in responses of Hong and Nga below.

> *My parents were passed away. Other siblings were living far from us. We had to do all by ourselves* (Hong).

> *My parents-in law did not care for him since he was diagnosed with ASD. We lived in the same ward, but they rarely visited our family and saw how was going with my child* (Nga).

4.5.4 Parents' perception of support

(i) Unhelpful support

Seven parents perceived that support sources that they received was limited and not helpful for them in addressing behaviour support needs. For example, Duc shared '*When my son received an ASD diagnosis, my wife participated in a three-day training course on ASD provided by a centre in Ho Chi Minh City. However, they just provided basic information. In my opinion, it was not so effective*'.

This perception was further highlighted in other parents' responses, as reported by Huong '*Materials that they gave to me were good to read. However, it was hard to practice in reality'* and Nga *'No, I thought it was not helpful. Doctors just asked some questions regarding my son's health history and then diagnosed him with mild ASD. They then gave me their phone numbers and told me to call them if I needed help'.*

(ii) Helpful support

Only one participant perceived social network was helpful for her, stating '*I thought parents sharing with each other like that would help us know that we were not alone'* (Mai).

Two parents felt that the support they received from their family was helpful. For example, Hien stated "*My parents supported me a lot. They were so helpful to me. Until now, I could not overcome difficulties without their great help'.*

4.6 Parents' support needs

Parents included in this study expressed a variety of needs that would be helpful for them in providing behaviour support to their children with ASD. These needs included (i) a desire for more information about ASD and behaviour support strategies, (ii) financial assistance to access behaviour support services, and (iii) accessible and affordable services relating to ASD and behaviour support.

4.6.1 A desire for more information about ASD and behaviour support

All ten parents desired to have more information about ASD and support strategies so that they could provide better support to their children. For example, Hien responded '*My biggest desire was to gain more knowledge and skills to control my child's behaviour'.*

This desire was also highlighted in some of their responses below.

> *I hope to know more about this disability to understand why my child presented such behaviours, when they would occur and how to respond to them. Thanks to*

this, I could him prevent challenging behaviours and develop good behaviours (Hong).

For parents, I wished to attend training courses on ASD, related challenging behaviour and effective support strategies (Huong).

4.6.2 Financial assistance to access behaviour support services

All ten participants reported the need for finance assistance to access support services was also reported by all ten parents in this study. First, financial assistance was for parents to participate in training courses related to ASD and behaviour support strategies which would help them provide better support to their child. For example, Huong reported:

I hope to receive financial support to attend training courses on behaviour support strategies that I could apply to my child. In Vietnam, these courses were only available in Hanoi, Danang or Ho Chi Minh City but their costs were too high, in addition to costs for food, accommodation and transportation.

This need also reported by Lan *'It would be good to receive cost aid to attend training courses on intervention strategies. Some parents could not afford to attend due to their costly'*.

Secondly, financial aid to access services for their children was also reported by all parents in this study. For example, Nga reported '*I hope to get financial support so that I could access services for my child, for example, regular visits to doctors and use of behaviour support services. These services were very costly'*.

4.6.3 Accessible and affordable services on ASD and behaviour support

All ten parents reported their desire to have accessible and affordable services on ASD and behaviour support in Quang Binh Province so that they and their children could access.

For parents, they wished to have services in Quang Binh that could provide them with knowledge of ASD and related information because available local services would help them reduce financial burdens. For example, Nhu reported:

> *I hoped in Quang Binh there would be available centres or organizations that provided consultation and support services for families of children with ASD. If so, parents would access to improve our child's behaviours. We would not need to travel to far places, so we could save costs'*

Nine other parents also concurred with Nhu in a hope to have accessible and affordable services for parents and children with ASD in Quang Binh Province. This could be seen in their responses below.

> *I really hoped that there would be available services on behaviour support strategies in Quang Binh soon so that parents could access for our children. It was fine if they were provided by private organizations. However, it would be better if offered by the government as we could reduce lots of costs* (Huong).

> *I just needed public educational centres for children with ASD where parents could send their children there. The government should also issue policies to support parents in raising and supporting children with ASD, especially providing free training courses on behaviour support for parents* (Lan).

4.7 Summary

Data collection from parents of children with ASD through in-depth semi-structured interviews was presented. All participant information was de-identified. Parents' age ranged from 28 to 52. Eight parents got married and lived with their immediate families, including the child with ASD. Seven parents were from rural areas and eight parents were working. Nine children were diagnosed with ASD. Only seven children were attending schools. One of parents' strengths identified was the use of preventative strategies to provide support their child, including modifying the environment, increasing predictability

of upcoming events, distraction and punishment. Parents' strengths also included their responsibility to take care of and unconditional love for their child, which were perceived as the most effective foundations in providing effective behaviour support. Limited knowledge regarding ASD and behaviour support, financial burden, time-limitations and stigma and cultural attitude were considered as challenges for parents in accessing relevant services. At the time of this study, parents were receiving support from family, social networks and professionals, but their perceptions of helpfulness of these supports varied, with some parents reported that this support was not sufficient specific to behaviour support. The need for more information and accessible and affordable support services relating to ASD and behaviour support were emphasised by all ten participants.

CHAPTER 5
DISCUSSION AND CONCLUSION

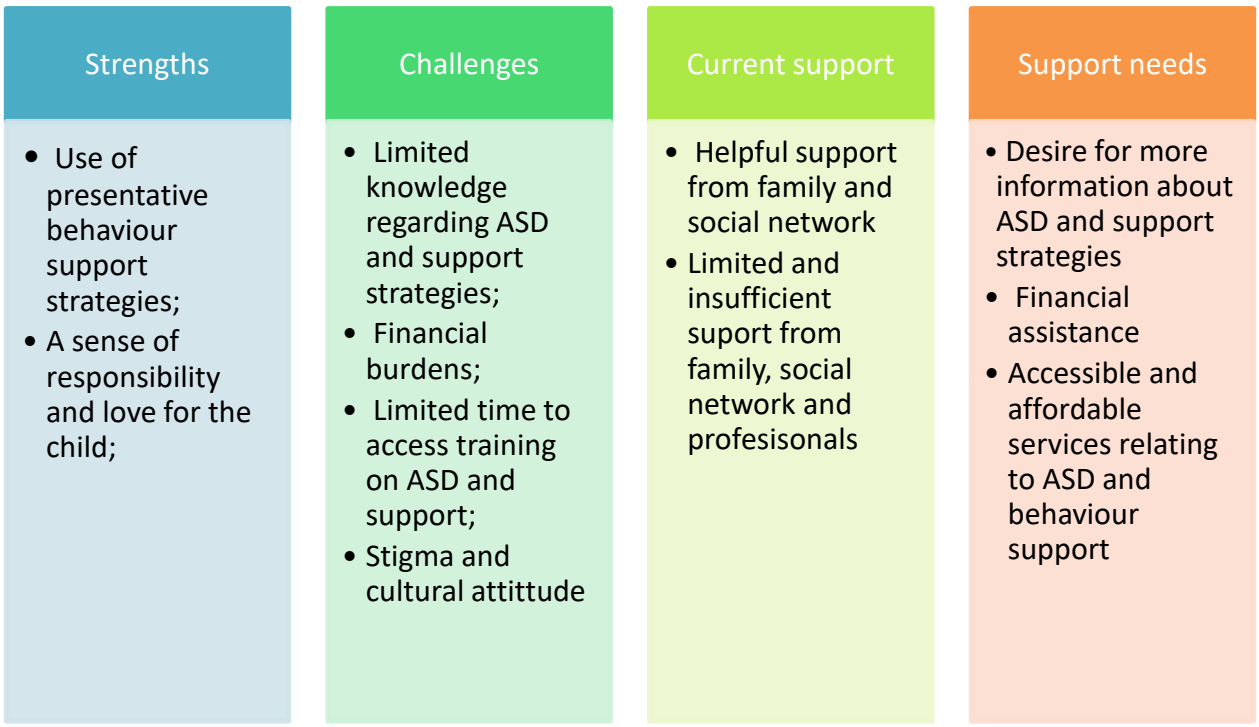
5.1 Introduction

This research explored parents' experiences in providing behaviour support to their children with ASD in Quang Binh, Vietnam. This was achieved by using a phenomenological approach, consisting of interviews with ten parents. Within this chapter, findings will be discussed according to the research aims and the ecological systems theory. The strengths and limitations of this research will then be presented, followed by recommendations for policy and practice and future research.

5.2 Integrating the research results into the theoretical framework

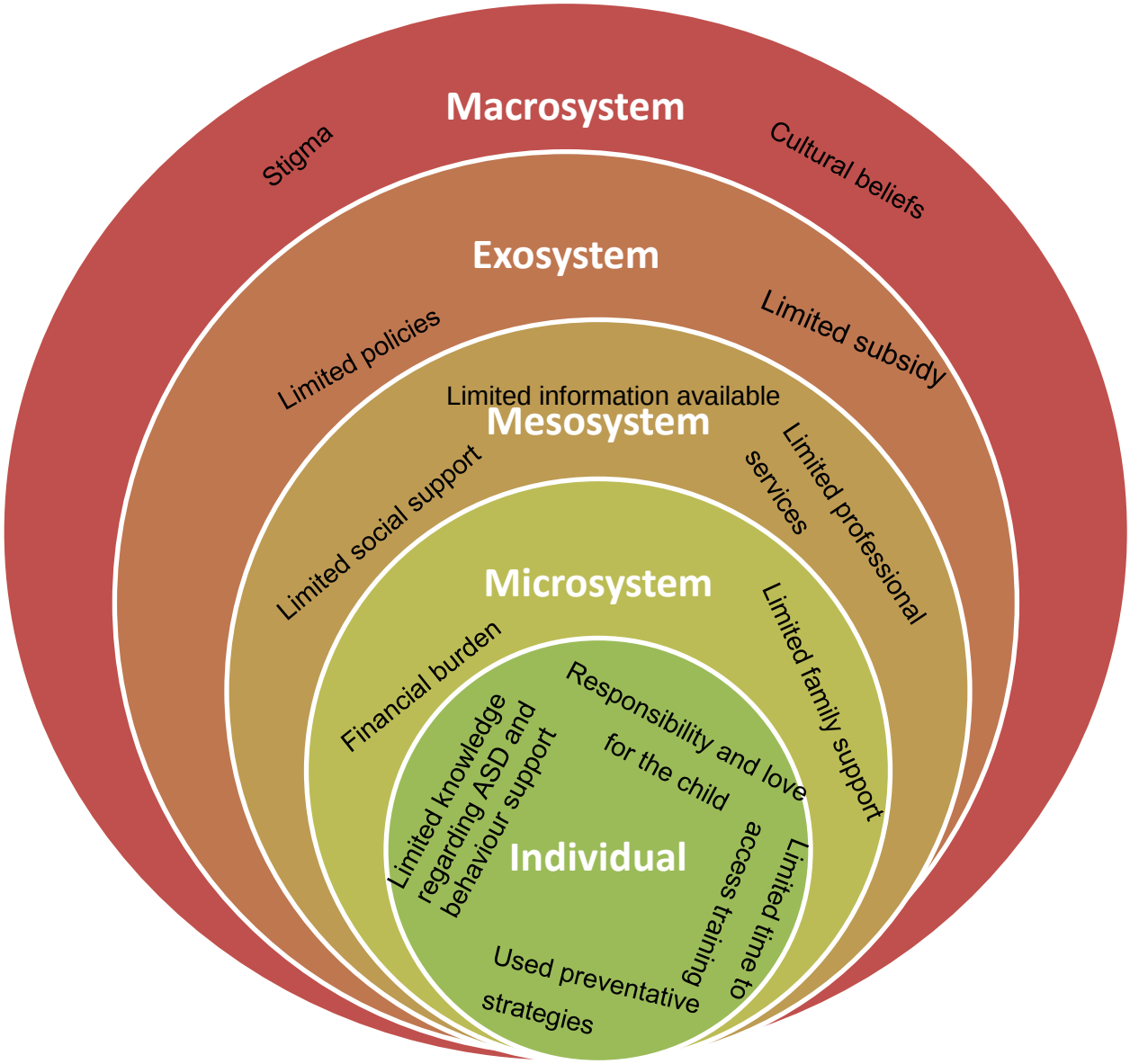
The ecological systems theory (Bronfenbrenner, 1989) outlined in Chapter 3 provides a framework for examining how an individual is impacted by his or her environmental systems. These include, the microsystem, mesosystem, exosystem and macrosystem. Using this systems lens to interpret the findings allowed the researcher to gain preliminary insights into how these systems may influence the parents' experiences in providing behaviour support to their children with ASD in Quang Binh, Vietnam. The key themes identified relating to parents' experiences include (1) strengths (use of preventative behaviour support strategies, a sense of responsibility and love for the child), (2) challenges (limited knowledge regarding ASD and behaviour support, financial burden, limited time to access behaviour support training and stigma and cultural attitude), (3) current support (mixed perception of support from family, social network and professionals), and (4) support needs (a desire for more information about behaviour support, financial assistance, accessible and affordable behaviour support services). These themes are presented in Figure 5.1.

Figure 5.1: Parents' experiences in providing behaviour support



These themes are also illustrated within their corresponding systems within the ecological systems theory in Figure 5.2. Each ecological system will be discussed separately according to parents' experiences; however, there will be some overlap given that these systems do interact with and influence each other.

Figure 5.2: Factors influencing parents' experiences in providing behaviour support to children with ASD in Quang Binh, Vietnam according to the ecological system theory



5.3 Parents' strengths

At the individual level, parents reported using preventative behaviour support strategies to proactively address challenging behaviours presented by their child, which was also

reported in previous research such as Ludlow et al. (2012), Sears et al. (2013), Whitaker, Joy, Edwards, and Harley (2001) and Desai, Divan, Wertz, and Patel (2012). Three parents reported increasing predictability of upcoming events/environments to their child. Parents reported that, before taking their child somewhere, they would provide her or him with information about the location, how long it would take to get there, what the environment looked like, who they would meet and why they were going there. The parents felt that enabling their child to anticipate future events helped them accept the situations and reduce their challenging behaviour. Increasing the predictability of upcoming events used by parents in this study were also reported in literature (Duignan & Connell, 2015; Fettig et al., 2015; Ludlow et al., 2012). Studies conducted in the UK by Ludlow et al. (2012) and in Australia by Duignan and Connell (2015) reported that informing their child upcoming events/environments in advance contributed significantly to the child smooth transitions between activities and their willing to accept new things, which subsequently resulted in reduction in their challenging behaviours.

Four parents also reported that they modified their home environment, including locking the gate to prevent their child from running out on the road and moving household items so that they were out of reach of the child (to prevent property damage and potential harm if thrown by child when they become 'overwhelmed'). Although these are restrictive practices, with preventative strategies being best practice (Neitzel, 2010; Roberts & Prior, 2016), these are considered as strengths given the orientation on preventing harm of the child and others.

All ten participants reported responding to their child's challenging behaviours by distracting them. This finding was in line with previous studies such as Marquenie et al. (2011) and Sears et al. (2013), in which parents reported using distraction as a way to manage challenging behaviours presented by their child. Distraction can be a great tool when faced with challenging behaviours (Whitaker et al., 2001). However, parents are recommended to use this strategy at an early stage of presence of challenging behaviour

and with minor challenging behaviours, not aggression and not very destructive behaviours (Whitaker et al., 2001).

None of the parents in this study reported any specific strengths regarding their experiences in providing behaviour support. This is not surprising given that literature revealed many challenges faced by families and that these are likely to overshadow their ability to see their strengths (Divan et al., 2012; Ludlow et al., 2012). However, the use of the preventative behaviour support strategies mentioned previously could certainly be perceived as parents' strengths. Furthermore, all ten parents' responses revealed a sense of responsibility in their support role, and an unconditional love for their child. Indeed, the responsibility and love for their child could be considered the most important foundation for providing effective behaviour support.

5.4 Parents' challenges

Challenges in providing behaviour support faced by parents in this study include limited knowledge regarding ASD and behaviour support, financial burdens and limited time to attend training on ASD and behaviour support, which were also broadly indicated in research in developed countries. Key issues raised across previous studies included negative discrimination from the community, shortage of information related to ASD and behaviour support, costly services related to ASD and limited formal and informal support (Divan et al., 2012; Foo, Yap, & Sung, 2015; Wodehouse & McGill, 2009). However, to date, there has been no peer-reviewed research conducted in Vietnam. Parents in this preliminary study reported significant challenges in providing behaviour support to their child with ASD, which will be discussed in relation to each level of the ecological systems theory.

At the individual level, parents reported having limited knowledge regarding ASD and behaviour support. This may have been impacted by their ability to access information. There is a lot of information on ASD, challenging behaviours and behaviour support strategies available online via websites in Vietnamese (was translated from English

sources) and English such as http://www.raisingchildren.net.au (Raising Children Network, 2017), http://www.autismspectrum.org.au (Autism Spectrum Australia, n.d), http://www.vinmec.com (VINMEC International Hospital, 2019). However, parents in Quang Binh may not have access to the internet and insufficient comprehension of English, which may prevent them from accessing these valuable sources of information. Parents' lack of knowledge could also be a result of broader societal issues regarding late recognition of ASD and limited information available for parents in Vietnam, which will be discussed in the mesosystem and exosystem below. This current research suggests the importance of face-to-face and individualised support for parents, allowing for interactive support from professionals.

Parents also reported limited time to attend training/workshops regarding behaviour support. All ten parents acknowledged that they could support their child better at home if they participated in related training/workshops. However, seven out of ten parents expressed challenges in arranging time to attend these training courses. Eight parents were working as full-time employees at the time of interviews. In Vietnam, full-time employees can take a maximum of 12 days on annual leave (The National Assembly, 2012), which may not be sufficient for families living in rural areas given that training is often available in big cities with more than three-days per training. For example, the training course on early intervention provided by Children's Hospital 1 (2018) lasted three days and was organized in Ho Chi Minh City. If parents wanted to attend this course, they must have at least seven days off (four days for transportation from Quang Binh to Ho Chi Minh City and vice versa and three days for training). Further, it has been suggested that parents need to take continuous courses in order to master strategies to effectively support their child. As a result, time arrangement for behaviour support training is a big challenge for some parents.

At the microsystem, parents reported financial burden in accessing support services. Behaviour support services, as mentioned above, are currently only available in urban cities such as Hanoi, Danang and Ho Chi Minh City. This may present barriers for families

living in countryside areas. A majority of participants (n=7) in this study were living in rural areas with disadvantaged social and economic conditions. Further, such services are costly while many parents reported to receive limited or no financial support from the government. Only three parents reported that their child with ASD were receiving a monthly subsidy of approximately 400 Vietnam Dong (AUD25). However, this amount was much little compared to that of service fees that parents had to pay, approximately from three million to five million Vietnam Dong (from AUD200 to AUD250) per month (Nga, 2019; Thanh, 2019). As a result, parents could not afford to access behaviour support services for them and their child. This study finding is consistent with previous research in the UK conducted by Hall and Graff (2010), who also found that parents of children with ASD experienced financial challenges in accessing behaviour therapy for their child.

At the mesosystem and exosystem, there are limited laws and guidelines specific for children with ASD and their families in Vietnam, in addition to late recognition of and limited information regarding ASD and challenging behaviour in Vietnam. Ying et al. (2012) and Motchan (2012) have suggested that ASD and its symptoms in Vietnam have just been recognised in the late 1990s. Furthermore, it has been suggested that policies for children with ASD and their families in Vietnam has not specified, but rather been included generally in legal documents, and social protection programs for children and people with disabilities (Manh Hoa, 2018; Vinahealth, n,d), for example, in Article 44 Chapter 8 of the National Law on People with Disabilities outlines the social welfare and monthly financial assistance for families of children with disabilities. However, only families of children with ASD who are identified as profound disability are eligible to receive monthly subsidy (National Assembly of Vietnam, 2010). Moreover, the National Law on People with Disabilities – the most powerful/effective document to date has not categorised ASD as a specific type of disability, but rather included it under ‘other disabilities’ (National Assembly of Vietnam, 2010). It has been suggested that this causes difficulties for parents in getting diagnosis and a certification of disability for their child to

receive the subsidy from the government, seeking information and accessing services for their child (Vinahealth, n,d).

At the macrosystem, parents in this study reported experiencing stigma and discrimination from their communities because of their child's disability and challenging behaviours. This was also reported by Vu et al. (2014) who have found that children with ASD and challenging behaviour and their families experienced various forms of stigma and discrimination such as labelling, worthlessness and a burden toward the child caregiver. Further, as Ying et al. (2012) mentioned in their research, disability in Vietnam is still commonly viewed as 'a punishment for a person's sins in a past life or for the sins of the person's parents' (p. 289). Due to this traditional belief, parents who have a child with disability generally and with ASD particularly experience feelings of shame and guilt (Vu et al., 2014). The cultural view of causation (Ying et al., 2012) coupled with stigmas experienced by parents of a child with a disability in Vietnam (Motchan, 2012) could cause challenges for parents in providing behaviour support to their child in public places that was reported by parents in this study.

5.5 Parents' current support

This study found that parents received and accessed a variety of supports to their child with ASD, which is consistent with previous research in the literature (Samadi et al., 2012; Searing et al., 2015; Wodehouse & McGill, 2009). At the microsystem level, parents reported different experiences in receiving support from family. Three participants considered family as a helpful source of support for them in providing behaviour support to their child. This support, mainly from their partners and grandparents of the child, included love for and care of the child. Meanwhile, seven parents reported not receiving support from their family. This is consistent with findings from the research of Samadi et al. (2012), who investigated the information and support needs of 43 parents of children with ASD and challenging behaviours in Iran. The Samadi et al. (2012) study suggested that a majority of Iranian parents lacked support from their immediate and extended families, similar to that found with Vietnamese parents in the present study.

At the mesosystem, there were two sources of support available to parents in this study. The first was peer support provided by other parents in similar situations; however, six parents felt this was not helpful specific to behaviour support. Previous research suggested that connecting with other families who experience the same situation could provide parents with good opportunities to access information and share experiences (Samadi et al., 2012). Responses from parents in the current study suggest that no informal organisations, such as peer support groups in which parents could share information and provide peer support in raising and supporting their child, were available in Quang Binh. Parents perceived support from their peers as unhelpful because they saw this support as providing empathy, encouragement, and understanding of family daily challenges.

Additionally, parents receiving limited support from their network may be associated with cultural views of disability in Vietnam. This led to parents to withdraw from socialisation with others in the community as reported in the study of Vu et al. (2014). Subsequently, parents do not know other parents experiencing similar situations to build their social networks and legitimise their experiences and share solutions with others experiencing similar challenges. This is particularly true with parents who live in rural areas as reported by parents not only in the current study but also previous research. For example, Hoogsteen (2011) and Samadi et al. (2012) conducted their research in Canada and Iran respectively reported that families of children with ASD who lived in rural areas experienced an increase in their social isolation.

Professionals were another source of support for parents at the mesosystem. All families reported experiencing supports from professionals such as paediatric doctors and therapists after their child's diagnosis of ASD. Some parents whose child were attending special schools also reported receiving support from educators. This support included receiving information relating to ASD and challenging behaviours, introduction of behaviour support strategies and medications. However, all parents felt this support was not helpful. This was partly due to geographical location and costs. As mentioned earlier,

services relating to ASD and challenging behaviours are expensive and currently only available in cities such as Hanoi, Danang and Ho Chi Minh City, which are far from Quang Binh. Thus, parents could not afford to pay regular visits for their families. Furthermore, even when parents accessed services for their child, they received 'rushed' and insufficient support from doctors and other specialists. Parents' dissatisfaction regarding professional support may also be associated with limited information regarding ASD and challenging behaviour in Vietnam as discussed above and reported in previous studies (Vu et al., 2014; Ying et al., 2012). This suggests a lack of services and experts in this area. This is also supported by a study of Wodehouse and McGill (2009), who investigated parental perception and concerns regarding support of 13 mothers of children with challenging behaviours in the UK. Findings from Wodehouse and McGill (2009) study suggested that parents of children and young people with developmental disabilities and challenging behaviour experienced problems with accessing services, gaining relevant information, ineffective strategies and a shortage of expertise.

5.6 Parents' support needs

At the individual level, it is not surprising that all parents reported a desire for more information about ASD and behaviour support. Currently, there are no books on ASD and challenging behaviours published in Vietnamese. Parents in this study reported receiving information mainly from the Internet (information was translated from English sources), while parents in developed countries could access a range of information sources including books, websites and peer support (Samadi et al., 2012). This finding is consistent with previous studies in the UK (Hall & Graff, 2010) and Iran (Wodehouse & McGill, 2009), which suggested that parents wanted more information about ASD and behaviour support strategies to provide support for their child at home.

At the microsystem, participants in this study reported financial assistance in accessing behaviour support services for their children. Parents are likely to have more opportunities to attend training courses related to ASD and behaviour support if they receive financial support or these services were freely available or less costly. The needs for financial

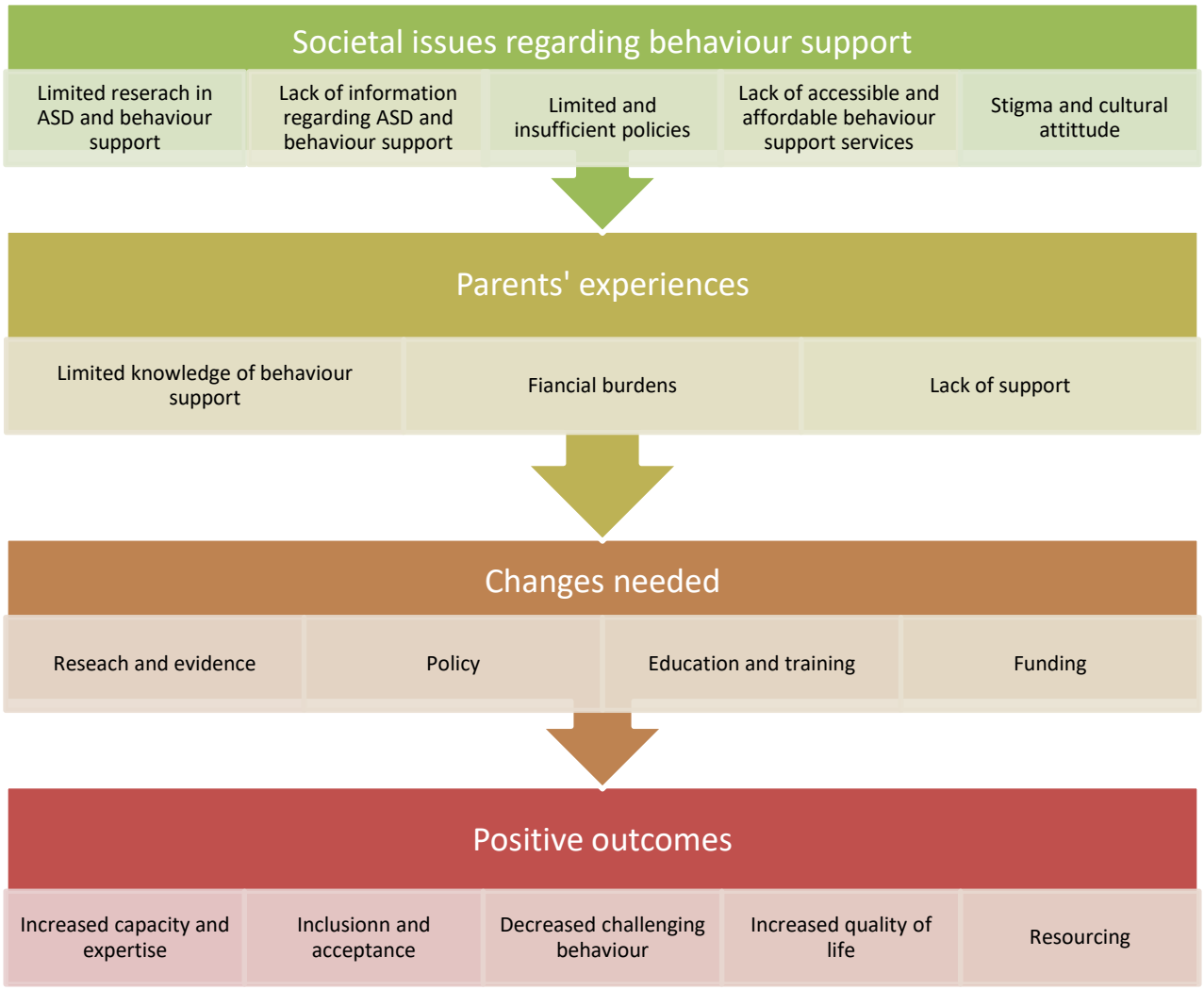
assistance of parents who have a child with ASD and challenging behaviours were also highlighted in previous research conducted in other countries. For example, parents in the studies conducted in the Southeast US by Hall and Graff (2010) and undertaken in Iran by Samadi et al. (2012) also wanted to receive financial assistance to access behavioural therapy for their child

At the mesosystem and exosytem, participants reported the desire for accessible and affordable services relating to ASD and behaviour support in Quang Binh. This is understandable because a majority of parents were living in rural areas with low income and limited or no financial support from the government. Moreover, they could not afford to regularly travel to big cities to access services for them and their child. This finding emphasizes the importance of the availability of local service provision to increase the accessibility of services for parents.

5.7 Lack of expertise

Synthesis of all findings from this study has suggested a lack of Vietnamese-specific expertise in behaviour support. This is a result of societal issues including limited research and evidence in ASD and behaviour support, limited and insufficient policies, inaccessible and unaffordable services, and stigma and cultural attitude. They were all themes that emerged from this research, reflecting parents' experiences in limited knowledge of behaviour support, financial burden and a shortage of support. Although there is a small sample size, these themes are consistently reflected in literature in other countries, including Iran (Samadi et al., 2012), India (Desai et al., 2012; Divan et al., 2012), New Zealand (Searing et al., 2015), and Singapore (Foo et al., 2015), which emphasises a significant gap in expertise in behaviour support in developing countries. Thus, it is suggested that there is a need for further research to gain further insights into parents' perspectives, but also a need for resources and policy changes in behaviour support in Vietnam more broadly. The suggested development of expertise and a framework in behaviour support in Vietnam is illustrated in Figure 5.3.

Figure 5.3 Development of expertise and framework in behaviour support in Vietnam



These suggested changes in research and evidence, polices, education and training and funding will build capacity and expertise in behaviour support for parents, professionals and academia, which will likely have an impact on a decrease in the child's challenging behaviours and an increase in the quality of life of both the child and his or her family. More importantly, this development would create valuable resourcing in behaviour support for parents of children with ASD in Vietnam in the future.

5.8 Recommendations

5.8.1 Recommendations for policy and practice

The aim of this study was to gain preliminary insights into parents' experiences in providing behaviour support to children with ASD. The preliminary findings were in the context of parents' strengths, challenges and support needs in behaviour support, the following recommendations should be considered.

- The Government should investigate the significance to develop expertise in behaviour support including parents, professionals and academia. The development of experts and a guiding framework could be done through changes in research and evidence, policy, education and training and funding.
- Further study on issues and practices in behaviour support should be developed.
- Services locally available would be easier and affordable for parents to access. Provision of allied health professionals at provincial and district hospitals should be taken into consideration. Face-to-face and individualised support for parents should be also developed.
- Translating information from international research and resources into Vietnamese is beneficial to not only professionals but also parents in accessing updated evidence-based information relating to ASD and behaviour support strategies for the child and family.
- Establishing a group of parents of children with ASD should also be considered. Peer support is an effective approach to help parents connect each other and share their experiences in raising and supporting their child.
- Awareness raising campaigns should also be supported to increase awareness of ASD and challenging behaviours for the community so that they could have a better understanding of this disability and positive attitudes towards children with ASD and challenging behaviours as well as the child's family.

5.8.2 Recommendations for future research

Although this research has gained preliminary insight in parents' experiences in behaviour support to children in Quang Binh, Vietnam, further research is needed, including:

- Research with larger sample sizes to gain further insights of parents' experiences in providing behaviour support to children with ASD.
- Research employing face-to-face interviews and focus groups discussion should be considered. These methods would enable the researcher to develop rapport responding body language allowing a more in-depth discussion with participants and further triangulate data.
- Research examining best methods in providing behaviour support to families.
- Further examining how factors at the Mesosystem, Exosystem and Macrosystem impact on parents' experiences in providing behaviour support.

5.9 Strengths and Limitations

This thesis provides an important contribution to literature in Vietnam by providing premilitary insights into parents' experiences in behaviour support in rural areas. In this study, parents who are primary carers of children with ASD were invited to share their lived experiences. The family perspective is key in understanding how different levels influence their behaviour support to their child and informing practices that need to be responsive to family needs. Further, the researched topic has not yet been investigated before in Vietnam generally and in Quang Binh particularly. Thus, the results from this preliminary research will provide significant foundations for policy makers, professionals and future researchers who are interested in behaviour support in Vietnam.

There are a number of limitations that should be acknowledged. This study used a relatively small sample size with one father and nine mothers. Although the larger sample of mothers is representative given that mothers often provide primary support (Safe et al., 2012; Smith et al., 2010), this preliminary research may underrepresent valuable experiences of other fathers. Further, the experiences of parents in the present study

could not necessarily be representative of other parents who have a child with ASD in Quang Binh and Vietnam.

There were also limitations regarding the mode of communication between the researcher and participants. Data collection was conducted via telephone and Facebook leading to limited contact between the researcher and participants. This was because the research participants were living in Quang Binh, Vietnam, while the researcher was in Australia. The researcher did not have direct communication with and observation of participants while interviewing, which may influence the researcher's ability to fully understand participants' responses. Member checking of interview transcripts, however, was used to reduce potential impacts on the result interpretation.

Finally, although interview questions were designed in English, they were conducted in Vietnamese and data were then translated into English for coding, analysing and interpreting. The researcher had difficulties in translating interview questions to collect data from English to Vietnamese and vice versa due to a fact that some English words may not match the exact meaning in Vietnamese causing confusion for participants. Take 'challenging behaviour' as an example. This noun phrase could mean "hành vi có vấn đề" or "hành vi thách thức" in Vietnamese. To delimit this, a native speaker with research experiences who is proficient in Vietnamese and English, employed to assist with interview transcript analysis. This action helped increase the study accuracy and credibility by triangulating data from different sources.

5.10 Conclusion

This dissertation aimed to explore the experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam. This was achieved using a phenomenological approach, with ten parents interviewed to investigate their strengths, challenges and support needs in providing behaviour support to their child.

The findings were discussed within the ecological systems theoretical framework in order to understand how each system impacted on a parent's' experience in providing behaviour support to their child. Throughout levels of the ecological systems, parents reported strengths only at the individual and microsystem level including the use of preventative behaviour support strategies, responsibility and unconditional love for their child. Meanwhile, parents faced challenges in behaviour support at all levels. At the individual level, parents reported limited knowledge regarding ASD and limited time for behaviour support training. At the microsystem level, financial burden and limited family support were perceived as barriers for parents in providing behaviour support to their child. Limited information regarding ASD and behaviour support, lack of support from social network and professionals, and insufficient policies are factors at the mesosystem and exosystem levels challenging parents in support their child. At the macrosystem, parents are challenged by stigma and culture belies in providing behaviour support to their child. Based on their experiences, parents expressed the needs specific to behaviour support including more information about ASD and behaviour support, financial assistance, and accessible and affordable services related to ASD and behaviour support.

Synthesis of findings in this research highlights a lack of expertise in behaviour support in Quang Binh, Vietnam. Findings were discussed in the broader context of Vietnam, with recommendations for further research to inform an optimal service model, including policies and best-practices in providing behaviour support for individuals with ASD and their families in a Vietnamese context.

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Appendix A: Letter of Introduction

Disability and Community Inclusion
College of Nursing and Health Sciences
Flinders University
Bedford Park
GPO Box 2100

Adelaide SA 5001
Tel: +61 (8) 8201 2576

3rd December 2018

LETTER OF INTRODUCTION

(for parents of children with ASD)

Dear Sir/Madam,

This letter is to introduce Tran Thi Dung who is a Master student in the College of Nursing and Health Sciences at Flinders University, Adelaide, Australia. Dung is undertaking research that she hopes to publish. This research is about provision of behaviour support to children with Autism Spectrum Disorder (ASD). The aim of the study is to understand experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam.

Dung would like to invite you to assist with this project by participating in an interview. This will take approximate 45-60 minutes and will be carried out according to your preference and convenience such as Facebook, Skype or telephone.

Please be advised that while all information provided will be treated with the strictest confidence by the researcher and none of the participants will be individually identifiable, it will not be possible to guarantee anonymity and confidentiality for interviews conducted via Facebook or Skype. However, please be assured that the only people who will have access to your information are the researchers. All names will be changed in the final report and any other places it is published.

You can withdraw from the study at any time, and you do not have to answer any questions that make you uncomfortable.

Dung will make an audio recording of the interview. She will ask your permission to record the interview and to use your results in preparing a report. No one will know your name or identity except the researchers involved in the study.

If you are interested in this study, please complete and return the Consent form for research participation attached in this letter and return to the researcher via email tran0393@flinders.edu.au before 1st January 2019 to register your participation. The researcher will then contact you directly to arrange interview time.

If you have any questions or concerns about the interview, research project, or risks or discomforts, please do not hesitate to contact me by telephone on +61 (8) 8201 2576, or email alinka.fisher@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,

Alinka Fisher, PhD

Associate Lecturer, Disability and Community Inclusion
College of Nursing and Health Sciences
Flinders University

This research project has been approved by the Flinders University Social and Behavioral Research Ethics Committee (Project number: 8180). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix B: Information Sheet

Ms Thi Dung Tran
Disability and Community Inclusion Unit
College of Nursing and Health Sciences
Flinders University
Sturt Road
Bedford Park
GPO Box 2100
Adelaide SA 5001
tran0393@flinders.edu.au
http://flinders.edu.au/mnhs/

CRICOS Provider No. 00114A

INFORMATION SHEET

(for parents)

Title: Examining the experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam

Researcher:

Ms. Thi Dung Tran
Disability and Community Inclusion
College of Nursing and Health Sciences
Flinders University
Email: tran0393@flinders.edu.au

Supervisors:

Dr Alinka Fisher
Disability and Community Inclusion
College of Nursing and Health Sciences
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Tel: +61 8 8201 2576
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Associate Professor Caroline Ellison
Disability and Community Inclusion
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 3422
Email: caroline.ellison@flinders.edu.au

Description of the study

This study is part of the project titled 'Examining the experiences of parents in providing behavior support to children with Autism Spectrum Disorder (ASD) in Quang Binh, Vietnam'. For the purpose of this study, 10 parents will be interviewed in order to gain insight into strengths, challenges and support needs of parents in providing behaviour support. The outcomes of this study will provide relevance for future researchers and professionals interested in behaviour support in Vietnam. This project is supported by the College of Nursing and Health Sciences, Flinders University.

Purpose of the study

The purpose of this qualitative study is to examine the experiences of parents in providing behaviour support to children with ASD in Quang Binh Province, Vietnam.

What will I be asked to do?

You will be invited to participate in an interview with the researcher who will ask you a few questions regarding your experiences in providing behaviour support to your child who have ASD if you are interested in this study and meet following inclusion criteria:

- parents age above 18 and are living in Quang Binh Province
- have a child diagnosed with ASD and aged under 18
- able to communicate via email, Skype, Facebook or telephone

Participation is entirely voluntary. The interview will be conducted via Facebook, Skype or telephone (depending on your preference) and is expected to take approximately 45-60 minutes. You may answer 'no comment' or refuse to answer any questions, and

The interview will be audio recorded and transcribed. Data will be de-identified and stored on a password-protected computer for five years as required by research ethics at Flinders University.

What benefit will I gain from being involved in this study?

There has been a lack of research investigating the experiences of parents in providing behaviour support to children with ASD in Vietnam. By sharing your experiences, you will help us to explore strengths, challenges and support services experienced of parents in Quang Binh, which is important for future researchers and professionals interested in and providing behaviour support in Vietnam.

Will I be identifiable by being involved in this study?

Please note that while the information you provide will be treated with the strictest confidence, and no identifying information will be published, your anonymity cannot be guaranteed due to online interview methods to be used.

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced, please contact following counselling services:

1. Flinders University Counselling Service, Adelaide, South Australia on +61 8 8201 2118 or email counselling@flinders.edu.au. Appointments are available from Monday to Friday, 8:45 am to 5:00 pm. Please provide your full name and phone number in the email and a counsellor will contact you by phone.
2. Counselling, Research and Life Psychology JSC, Vietnam on 024 2211 6989 or email share@sharevn.org. Appointments are available from Monday to Friday, 8:00 am to 5:00 pm. Please provide your full name and phone number in the email and a counsellor will contact you by phone.

How do I agree to participate?

Participation is voluntary. If you are interested in this study, please complete and sign the consent form accompanying this information sheet and return to the researcher before 1st January 2019 at tran0393@flinders.edu.au to register your interest and arrange for interview.

You are free to withdraw from the interview at any time without effect or consequences.

Please be advised that the first 10 people who register interest and meet inclusion criteria will be selected for participation.

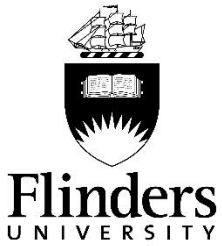
How will I receive feedback?

A copy of your interview transcript will be sent to you shortly after your interview. Please review the transcript and provide feedback on information presented.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8180). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix C: Consent Form and Contact Details For Participation In Research



CONSENT FORM AND CONTACT DETAILS FOR PARTICIPATION IN RESEARCH

(Interview)

Examining the experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam

I ….....

being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction for the research project titled 'Examining the experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam'.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I understand that:
    - I may not directly benefit from taking part in this research.
    - participation is entirely voluntary, and I am free to withdraw from the project at any time; and can decline to answer particular questions.
    - while the information provided will be treated with the strictest confidence, and no identifying information will be published, anonymity and confidentially cannot be guaranteed due to online interview method to be used.

- I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

5. I will be given the opportunity to review and edit my interview transcript soon after my interview.
6. I agree to contact the researcher directly for the interview arrangement.

Participant's name…….....

Participant's signature……Date……...

RESEARCHER'S CONTACT DETAILS

Please read this form carefully, complete, sign and return to the researcher via email tran0393@flinders.edu.au **before 1st January 2019 to register your interest.**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name…….....

Researcher's signature……..Date…….

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 8180). For more information regarding ethical approval of the project please contact the Executive Officer on (08) 8201-3116 or human.researchethics@flinders.edu.au

Appendix D: Interview Guide

I. Information about yourself

1. What is your name?
2. How old are you?
3. Your gender
4. Your marital status
5. Your living arrangement
   - Where are you living? In urban or rural area?
   - Are you living with your child? If no, where is your child is living? And with whom?
   - How many people are living with you? Who are they?
6. Your employment status
   - Are you working? Full-time or part-time?

II. Information about your child

1. What is your child name?
2. How old is she/he?
3. Has your child been diagnosed with ASD? If yes, when?
4. Which type of school that your child is attending and which grade?
   - Mainstream school
   - Special school

III. Let's talk about your experiences in providing behaviour support to your child

1. What behaviours of your child do you find challenging?
2. How do you respond to these behaviours?
3. Can you tell me about a time that you successfully deescalated a potentially challenging behaviour? How did you do that?
   - For example, a time that you prevented a behaviour escalating to something more challenging
4. Have you made changes to your environment to help reduce the likelihood of challenging behaviour occurring? If yes, could you give me some examples?
   - Using visual prompts
   - Reducing sensory stimulation

5. When providing behaviour support to your child, are there situations/context that you find easier or harder than the others? If yes, could you give me an example?
    - Places in community
    - With relatives/ unfamiliar people
    - Different times/routines

IV. Let's talk about the support needs

1. Have you received any support or accessed services to assist you with behaviour support for your child? If so, what is the nature of the support, who has provided this and for how long? Has this been helpful?
2. Is there any additional support/needs that you think would help you provide behaviour support to your child?
    - Knowledge/information
    - Finance
    - Support from family/organizations
    - Emotional well-being

V. Are there any further comments that you would like to share?

Appendix E: Ethics Approval

APPROVAL NOTICE

Project No.:	**8180**
Project Title:	Examining the experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam
Principal Researcher:	Ms Thi Dung Tran
Email:	tran0393@flinders.edu.au

Approval Date:	10 December 2018	Ethics Approval Expiry Date:	**30 June 2020**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comments.

Additional comments:

1. Please ensure that copies of the correspondence granting permission to conduct the research from the Association for Empowerment of Persons with Disabilities (AEPD) is submitted to the Committee *on receipt.* Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – number 8).

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (2007-Updated 2018)*an annual progress report must be submitted each year on the **10 December** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **10 December 2019** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.auimmediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Appendix F: Translation Accuracy Certification Form

Flinders University and

SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE

IMPORTANT – this form should only be completed for translations submitted after an ethics application has been submitted and reviewed by the committee; as the committee may request changes to the information and documents to be provided to prospective participants requiring translation.

TRANSLATION ACCURACY CERTIFICATION

Participant Documentation

PROJECT NO.	**8180**

Principal Researcher	Thi Dung Tran
Supervisor Name (student projects only)	Dr Alinka Fisher Associate Professor Caroline Ellison
Project Title	Examining the experiences of parents in providing behaviour support to children with ASD in Quang Binh, Vietnam.

Does your proposed research require documentation to be translated into another language?	x	Yes
		No

Place the letter 'X' in the relevant box

If NO, please note that this form does not need to be completed.
If YES, please complete the sections below.

		YES	Individuals Name or Company Name
HOW will information and documentation to be distributed to prospective participants be translated?	By the student researcher?	**X**	
	By the student's supervisor?		
	By one of the staff researchers?		
	By an employed research assistant?		
	By a professional translation company?		

Translations undertaken by a Third Party	**Principal Researcher / Supervisor Signature**
If information and/or documentation to be provided to prospective participants will be translated by a third party (i.e, research assistant / translation company etc), the committee asks that the principal researcher (or supervisor if a student project) please sign to the right to certify that accurate translations have been provided to the best of his/her knowledge.	_____ **Date:** ----------

Translations undertaken by Researcher	**Principal Researcher / Supervisor Signature**
If information and/or documentation to be provided to prospective participants will be translated by one of the researchers, the committee asks that the principal researcher (or supervisor if a student project) please sign to the right to certify that accurate translations have been provided to the best of his/her knowledge. Note – this section does not need to be signed if translations were undertaken by a third party.	 **Date:** 25 June 2019