The Lived Experience of Lao Families Having a Child with Autism Spectrum Disorder (ASD)

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DECLARATION

I certify that this thesis does not incorporate without acknowledgment, 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 in the text.

Viengsam Indavong
25th July 2017

SUPERVISOR'S CERTIFICATION

The researcher's supervisor confirms that she has approved all aspects of the research project detailed in this thesis, including the content of the literature review and the collection, analysis, reporting and storage of data.

Caroline Ellison
25th July 2017

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TABLE OF CONTENTS

ABSTRACT

The purpose of this current study was to explore parents' experiences of raising a child with Autism Spectrum Disorder (ASD) in Lao People's Democratic Republic (PDR). The experiences of 26 Lao parents were examined through a qualitative survey questionnaire. These participants described their insights into how having a child with ASD impacted on their feelings and emotions; financial circumstances; and participation in employment, family relationships, friendships and community involvement. Participants were also asked to share some of the strategies and supports they used in order to help them cope with their daily life, as well as other supports and approaches they believe may enhance their life in the future.

The findings from this study confirmed some universal experiences of parenting a child with ASD as well as uncovering experiences that were unique to the Lao context. Notably these involved a lack of government policy support, education and professional services. Lao families who have a child with ASD make great personal and family sacrifices to maintain education opportunities for their children. They face multiple levels of complexity especially associated with the lack of an ASD diagnosis.

This study provides recommendations regarding supports for families, professionals and for disability advocacy in Laos, based on evidence-based practices from around the world that can potentially be implemented at a reasonable cost. The findings of this current study serve to provide evidence for government policy makers, funding providers and public health and education officers to incorporate family support needs into policy, and support the need for collaboration with local and international researchers and donors. The need for a standardised ASD definition, assessment and diagnosis service was at the forefront of this research, followed by the need for ongoing education, professional development and further ASD research in Laos.

CHAPTER ONE

1. INTRODUCTION

The purpose of this current study is to reveal the experience of Lao families who have a child with Autism Spectrum Disorder (ASD). This research will determine whether the experiences of families in Laos are similar to those suggested in international and regional research. In order to understand these experiences, the researcher undertook a review of the existing literature on the lived experience of parenting a child with ASD in both Western and non-Western countries, and conducted primary data collection and analysis of responses to an open-ended survey questionnaire with parents who have a child with ASD in Laos.

1.1. Statement of the problem

Autism Spectrum Disorder (ASD) is a neurodevelopmental lifelong disorder with symptoms that appear in early childhood and cause the affected individual to face many challenges in life (American Psychiatric Association, 2013).

Deficits in social interaction and communication skills and restricted and repetitive patterns of behaviours limit the person's ability to function in their day-to-day activities and can cause them to become dependent on others (Ha et al., 2014; Smith, 2015).

It is these difficulties, related to behaviours of concern, that affect their participation in education, health care and community services, which can cause them to become isolated (Gardiner & Iarocci, 2012; Ha et al., 2014).

The World Health Assembly reiterated the commitment of member states to 'safeguard citizens from discrimination and social exclusion on the grounds of disability irrespective of the underlying impairment' and 'promoting all persons' basic necessities to life, education, health care and social security' (World Health Organisation (WHO), 2017 p.1)

People with ASD continue to face barriers in their participation in the community as equals with their peers.

In addition, globally the rate of diagnosis of autism continues to increase. The World Health Organisation (WHO) estimates 1 in 160 people have ASD. The prevalence rate of ASD estimates that 1 in 54 males born in the United States has the disorder (Centers for Disease Control, 2012). Parenting a child with ASD is very complex and stressful (Corcoran et al., 2015). While some people with ASD can live independently, others have severe disabilities and require lifelong care and support. It requires tremendous work and emotional efforts for parents to care for the child with ASD. The higher the severity of symptoms, the more the child is dependent on time, energy, money and support from parents, families, community and the government (Corcoran et al., 2015; Ha et al., 2014; Myers, Mackintosh & Goin-Kochel, 2009; Woodgate et al., 2008).

Despite increasing knowledge about the prevalence rate of ASD diagnoses and the impacts of ASD on families, the understanding of ASD across different cultural contexts is still limited, especially in under-resourced countries like Laos, Vietnam and Cambodia.

Therefore, the understanding of how ASD affects families in Laos is drawn mainly from the existing knowledge of the lived experience of families having a child with ASD in other countries.

1.2. Purpose of the study

The purpose of this current study is to reveal the experiences of Lao families who have a child with ASD.

Furthermore this current study aims to:

1. Gain a greater understanding of how ASD affects families across the different cultural contexts of life in Laos;
2. Understand the experiences of families in relation to emotional demands, finances, family life, coping and support needs.

1.3. Significance of the study

Kim (2011) states ‘autism transcends cultural, geographic, and ethnic boundaries and that autism is a major global public health concern, not limited to the Western world. To date, there is no evidence of differences in the way ASD is expressed in children around the world; however it is possible that cultural factors may impact diagnostic practices and prevalence estimates.’

WHO (2017) highlights that individuals with ASD and their families face major challenges including social stigmatisation, isolation and discrimination and that children and families in need especially in an under-resourced context, often have poor access to appropriate support and services.

It is vital that research is undertaken which seeks to understand how ASD affects families in developing countries. It has been noted that both Western and non-Western countries face challenges, complexities and resource deficiencies which create a universal experience for individuals and families dealing with ASD (Corcoran et al., 2015; Ha et al., 2014; Myers, Mackintosh & Goin-Kochel, 2009; Woodgate et al., 2008).

Parents are often faced with a variety of emotions during diagnosis and when they have difficulty accessing necessary services due to limited financial resources and public policy. Asian parents are confronted with additional distress related to discrimination which is linked to superstitious cultural beliefs (Ha et al., 2014).

Most studies have focussed on families from high income countries, such as the United States, Canada, and Australia where disability policies and services are well established to provide help for people with ASD and their families (Corcoran et al., 2015; Gardiner & Iarocci, 2012; Woodgate et al., 2008). However, the studies in non-Western countries, such as, China, Indonesia, Vietnam, Thailand, and Singapore revealed discrimination towards people with autism and their families is one of the major challenges they face. What remains unexplored is an examination of the lived experience of Lao families who have a child with ASD. The experience of Lao families may be different to other South East Asian countries due to government policy, community, education and health resource differences.

Laos, a lower-middle income country challenged by low available resources, was chosen because of recent developments in that country in the disability sector, in particular the ASD advocacy movement for parents who have a child with ASD. The United Nations Convention on the Rights of People with Disability (UNCRPD) (2006) was ratified in 2009 by the Lao Government and the Decree on Persons with Disabilities was adopted in 2014 (Handicap International, 2016). The official data on people with disabilities in Laos is still unclear (Handicap International, 2016). There is no official definition, assessment of, and diagnostic process for ASD in Laos (Association for Autism, 2016). Therefore, the visibility (presence) and identification of children or adults with ASD remains unidentified, as do their needs. Only a small proportion of families in major cities receive formal assessment and diagnosis by visiting hospitals in Thailand. Many of these families are the members of the parents' advocacy group movement of Association for Autism (AfA) in Laos.

This current study will provide insight into the experiences of families in Laos and consequently address a gap in the knowledge regarding ASD. This research will provide valuable evidence regarding the needs of individuals with ASD and their families in Laos to assist the Association for Autism (AfA) as it advocates for policy development. The results will inform future practice for AfA by identifying and prioritising their services to empower their members. Another benefit is to provide the basis for future studies in ASD related matters in Laos to further inform policy makers about the need for the implementation of evidence-based policy. Therefore, this current study is the first study researching the lived experiences of families who have a child with ASD in Laos.

1.4. Researcher's lived experience

In order to truly reflect Heidegger's philosophy of phenomenology (which will be introduced in Chapter Three), it is important to acknowledge the researcher's previous and current experience of the phenomenon. The researcher in this current study is the mother of a 10-year-old boy with ASD, Co-Founder, Former President and current Board Member of Association for Autism in Laos. With these experiences, the researcher acknowledges that her lived experience may impact on the way the data in this current research is interpreted.

1.5. Chapter summary

This chapter provided an introduction to the purpose and significance of this thesis. Background information regarding ASD and how it impacts families both in Western and non-Western countries was discussed. The gap in knowledge about Lao families' experiences was also identified.

1.6. Structure of the thesis

Chapter One presents an introduction to the thesis outlining the problem statement, purpose and significance of the study and the acknowledgement of the researcher's experience.

Chapter Two presents a literature review of perspectives on disability, defining Autism Spectrum Disorder (ASD) and how ASD impacts family life in both Western and non-Western countries. The chapter outlines the challenges faced by Asian families and implications found in the studies of countries along with an explanation of disability in the Lao context.

Chapter Three describes the research design and methodology and presents the research questions of this current study.

Chapter Four outlines the findings relating to Lao parents' experiences of having a child with ASD. It describes the key findings from the responses to the open-ended survey questions.

Chapter Five presents a discussion based on the findings, linking the experiences of Lao parents with parents in other countries and the literature regarding support services demonstrated to be effective in Western countries.

Chapter Six concludes the thesis with a summary of key findings and recommendations for further research and implications.

CHAPTER TWO

2. LITERATURE REVIEW

The purpose of this chapter is to conduct a literature review of the lived experience of parents of a child with ASD in both and Western and non-Western countries in order to identify common themes.

2.1. Literature review

A search for relevant articles to be included in the literature review was conducted. Searches of electronic data bases Scopus and ProQuest using the terms autism, ASD family, mothers, father, caregivers, experiences, and impact, stress with ASD, ASD in Western countries, Asia and Laos. The time period was from 2006 onwards. Eighty articles were found based on the inclusion criteria, which was reduced to 29 articles and included a combination of peer-reviewed journal articles and doctoral dissertations. Across the sample variety of methodologies were used to describe the lived experience of families who have a child with ASD. They included 16 qualitative studies, eight quantitative studies, three studies using mixed methodologies and two systematic reviews of qualitative papers.

Most studies in the sampled literature focussed on families from high income Western countries, such as the United States, Canada, and Australia, where disability policies and services are well established to provide help for people with ASD and their families. Studies of non-Western countries, such as, China, Indonesia, Vietnam, Thailand, and Singapore were also explored.

Eight themes emerged from the review: 1) parents' experience of difficult emotions; 2) coping/adaptation; 3) impact on family quality of life; 4) access to services/lack of professional services; 5) parenting style; 6) social and cultural belief/view on disability; 7) stigma/discrimination, and 8) financial and policy support to families. The top three themes were parents' experience of difficult emotions; coping/adaptation; and impact on family quality of life/cohesion/functioning; each of which will be described in turn below.

2.2. Defining disabilities

The World Health Organisation (WHO) (2017) defined disability as a condition whereby people experience an impairment in their body function or structure; a difficulty in carrying out a task or action (activity limitations); and a restriction in participation and involvement in life activities in the society in which they live. Types of disabilities are categorised by intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of those impairments (Government of Western Australia, 2017). The term disability used in this thesis refers to all types of disability as defined above. Those who are diagnosed with ASD will be referred to as individual with ASD or parents/families of a child with ASD.

2.3. Perspectives on disability

The field of disability is complex and issues cannot be dealt with separately (Lindsay, Greve, Cabras, Ellison & Kellett, 2015) therefore, it has become a multidisciplinary field covering social and behavioural sciences, humanities, and medical, rehabilitation and education (Berger & Lorenz, 2016; Lindsay et al., 2015). Therefore, there are many perspectives on disabilities that examine the reality of disability in different ways due to the history and movements in this field (Lindsay et al., 2015).

The medical model views disability as a disease which needs treatment by medical practitioners and this view has been the basis of disability since the 19th century (Lindsay et al., 2015; Sabatello, 2013). The medical model assumes disabled people need to be made normal. Discrimination occurs when people with disability are looked at as inferior, with no right to access the ‘good things’ in life (Lindsay et al., 2015; Sabatello, 2013). Families in Laos also often experience a tragedy/charity view of disability where those with disabilities are seen as victims of circumstance, and need pity. People with disabilities tend to be used to raise funds for the charity concerned. This view is disempowering for people with disabilities and impacts on their self-esteem (The Christoffel-Blindenmission [CBM], 2016). Recent opposition to this view has given rise to a perspective based on the philosophy of ‘normalisation’ whereby, since the late 1960s, Nirje suggested that people with disability should be given value and the opportunity to live a normal life without being institutionalised (Flynn & Lemay, 1999). Social Role Valorisation (SRV) developed when

Wolfensberger in 1983 expanded the normalisation principle (Flynn & Lemay, 1999). The concept of SRV is that people who have valued roles in the society are more likely to live happily and successfully in the society. On the other hand, SRV recognises that those with devalued roles such as people with disability and/or behaviour issues are viewed negatively by the society (Wolfensberger & Training Institute for Human Service Planning, Leadership Change Agency, 1991). Quality of life for people with disabilities is an important concept when looking at their lived experience. The right for a person with disabilities to have full participation in society and to lead a fulfilled life has seen the development of rights-based movements like SRV (Warren & Manderson, 2013) and people with ASD use terms such as 'neurodiverse'. Silberman (2011) highlights individuals who are neurological diverse do not need to be cured but accepted and their needs accommodated by society.

Developmental Education which is derived from Developmental Psychology and is sometimes referred to as the behavioural model, aims to teach social and independent living skills to people with intellectual and other forms of disability (Sabatello, 2013).

The social model of disability opposes the medical model by separating the concepts of impairment and disability (Hughes, 2010). The social model acknowledges that a long-term impairment may occur in an individual's body, mind or senses but suggests the disability comes from social barriers such as negative attitudes, lack of access to services and support experienced by the person with an impairment (Hughes, 2010). The social model of disability promotes choice and control, equality and opportunity for people with disability (Hughes, 2010).

2.4. Defining Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder (Hahler & Elsabbagh, 2014). The Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5) (American Psychiatric Association (APA), 2013) specifies that people diagnosed with ASD must present deficits in two domains which include (1) impaired social communication and social interactions and (2) restricted, repetitive patterns of interests, activities and behaviours (American Psychiatric Association (APA), 2013). Autism can affect the way individuals interact with others and how they experience the world around them. ASD affects individuals differently and there is a wide range in people's level of skills and the severity of their symptoms. Positive social interactions are dependent on the person's ability to communicate their needs, wants and ideas in social situations. Restrictive patterns of behaviour arise when people with ASD demonstrate a preference for routines and dislike change. When people with ASD have unusual reactions to sensory stimulation and demonstrate unusual patterns of behaviour other may judge them as being unusual.

The data released by the Centers for Disease Control and Prevention (CDC) identified the prevalence rate of ASD at 1 in 54 males at birth in the United States (Centers for Disease Control, 2012). While across Asia the rates of affected individuals vary widely, from 1 in 38 in South Korea (Kim et al., 2011); Singapore 1 in 150; Thailand 1 in 349; and Vietnam 1 in 535 (WHO, 2017). In Laos there is no data indicating the prevalence rates for the disorder, the Lao Association for Autism estimates a figure of 11,000 to 17,000 individuals in Laos who may have ASD based on rates in neighbouring countries.

Interventions for people with ASD need to be accompanied by broader actions for making physical, social and attitudinal environments more accessible, inclusive and supportive. Worldwide, people with ASD are often subject to stigma, discrimination and human rights violations. Globally, access to services and support for people with ASD is inadequate (WHO, 2017).

People with ASD experience many challenges throughout their lives (Ha et al., 2014). They often face significant difficulties in the processing of sensory information, which may limit or impair their everyday functioning across multiple contexts (American Psychiatric Association, 2014). Other challenges include reduced access to education, health care, and community activities, bullying and violence, isolation and dependency on others (Howlin, 2005; Ochs, 2001; cited in Ha et al., 2014).

Parenting a child with ASD has been recognised as complex and intensive; it requires vigilance and is stressful by nature which impacts family functioning as a whole (Corcoran et al., 2015; Gau et al., 2012; Ha et al., 2014; Myers, Mackintosh & Goin-Kochel, 2009; Woodgate et al., 2008; Wang et al., 2013). In addition, families who have a child with ASD face financial burden and stigmatisation of their child (Corcoran et al., 2015; Ha et al., 2014; Woodgate et al., 2008).

2.5. Parents’ experience of difficult emotions

A number of studies which focussed on parents’ experiences revealed that families of a child with ASD face a variety of emotional stresses and tensions (Anh, 2015; Corcoran et al., 2015; DePape & Lindsay, 2015; Gardiner & Iarocci, 2012; Hoogsteen & Woodgate, 2013; Hutton & Caron, 2005; Jeekortok & Chanchalor, 2012; Lai et al., 2015; Larson, 2010; Lendenmann, 2010; Myers et al., 2009; Ogston et al., 2011; Smith et al., 2010; Wang et al., 2013; Woodgate et al., 2008). The complexity of the parenting role arises mainly from the dependency of the child with ASD accompanied by communication difficulties and behavioural problems beyond the years a parent would normally expect. The child’s difficulties require parents to provide intensive vigilant care, as well as perform multiple roles to balance family and individual needs for longer than a parent would normally.

Parents often reported limited personal time, feeling stress, frustration and worry, feeling isolated, missing a normal way of life and total life change (Corcoran et al., 2015; DePape & Lindsay, 2015; Gardiner & Iarocci, 2012; Hoogsteen & Woodgate, 2013; Hutton & Caron, 2005; Jeekortok & Chanchalor, 2012; Lai et al., 2015; Larson, 2010; Lendenmann, 2010;Myers et al., 2009; Ogston et al., 2011; Smith et al., 2010: Wang et al., 2013; Woodgate et al., 2008). The combination of emotional, social, educational, financial, psychological and physical aspects in raising a child with ASD contribute to the universally unique complexity of family functioning when parenting a child with ASD (Freeman et al., 2012; Gau et al., 2012; Hoogsteen & Woodgate, 2013; Lendenmann, 2010; Martinez, 2009; Ogston et al., 2011; Phelps et al., 2009; Robert et al., 2014).

However, some parents have also found many positive values associated with raising a child with ASD (Corcoran et al., 2015) the concept of appreciating their child's strengths and noticing their small accomplishments. The study by Kuhaneck et al. (2010) supports positive reframing being witnessed in mothers who see 'joy' and success in a child with ASD. Parents report gaining new knowledge about ASD and effective coping strategies which gave them a sense of empowerment and control (DePape & Lindsay, 2015; Hoogsteen & Woodgate, 2013; Kuhaneck et al., 2010; Lendenmann, 2010; Phelps et al., 2009; Robert et al., 2014).

2.6. Impact on the Family Quality of Life (FQOL)

Family Quality of Life (FQOL) refers to the wellbeing of the person with disability within the context of the family and the opportunity that family has to achieve their goals. ASD affected both individual quality of life and FQOL, cohesion and functioning (DePape & Lindsay, 2015; Freeman et al., 2012; Gardiner & Iarocci, 2012; Gau et al., 2012; Hoogsteen & Woodgate, 2013; Hunt-Jackson, 2007; Hutton & Carson, 2005; Kent, 2011; Larson, 2010; Lendenmann, 2010; Martinez, 2009; Myers et al., 2009; Phelps et al., 2009). According to Kohler (1999) and Lovett and Haring (2003), cited in Gardiner and Iarocci (2012), families face a number of day-to-day challenges that are complex, overwhelming and financially burdensome (Hunt-Jackson, 2007; Ogston et al., 2011; Wang et al., 2013). Families need to adjust (DePape & Lindsay, 2015; Kent, 2011; Ogston et al., 2011; Phelps et al., 2009; Woodgate et al., 2008) and are in need of professional support that is often limited.

Further, studies have found that families with a child with ASD reported lower marital satisfaction compared with families who have a 'typically' developing child (DePape & Lindsay, 2015; Freeman et al., 2012; Gardiner & Iarocci, 2012; Gau et al., 2012: Kent, 2011; Myers et al., 2009). Families with a child with ASD also find it difficult to maintain sibling relationships as siblings often feel guilty, hurt and confused (DePape and Lindsay, 2015; Gardiner & Iarocci, 2012; Gau et al., 2012; Kent, 2011; Myers et al., 2009; Ogston et al., 2011) and always have to strive to find balance in the family life (DePape & Lindsay, 2015; Hoogsteen & Woodgate, 2013; Santoso et al., 2015).

2.7. Coping and adaptation

As families experience varying degrees of complexity and emotional difficulties in life, they learn to cope, adapt and survive (Martinez, 2009; Anh, 2015; Santoso et al., 2015; Corcoran et al., 2015; Ogston et al., 2011; Gardiner & Iarocci, 2012; Myers et al., 2009; Hoogsteen & Woodgate, 2013; Schwartz, 2001; Hunt-Jackson, 2007; Lendenmann, 2010; Phelps et al., 2009; Kuhaneck et al., 2010; Freeman et al., 2012; Smith et al., 2010; DePape & Lindsay, 2015). The studies of Sturge-Apple, Davies and Cummings (2010; cited in Gardiner and Iarocci, 2012) and Ogston et al., (2011) identified some factors which protect against psychological distress and family dysfunction, such as, hope, access to extended family and social support, financial support, and quality of community support services. Access to these supports could help parents, especially mothers, to achieve 'personal time' and respite (Kuhaneck et al., 2010; Smith et al., 2010; Lendenmann, 2010; Hoogsteen & Woodgate, 2013; Gau et al., 2012; Larson, 2010) as well as, being able to help the child with ASD to access intensive individualised support services and therapies to improve social-communication skills, independent living skills and behavioural support intervention (Larson, 2010; Eskow et al., 2011 cited in Gardiner and Iarocci, 2012; Kuhaneck et al., 2010; Robert et al., 2014).

The study by Myers et al., (2009) highlights the significance of 'producing meaning' in life as a positive theme in which families find their way, making sense out of adversity and being able to cope (Frankl, 1984, cited in Myers et al., 2009). Scorgie and Sobsey (2000), and Hastings and Taunt (2002) cited in Myers et al. (2009) support this notion and coined the term 'transformation' to represent positive life-changing experiences of having a child with a disability which resulted in increased sensitivity, confidence and assertiveness, support for each other, improved dynamics in family life and being assisted by a strong religious faith.

Families develop resilience, which is enormously valuable when linked to adversity (Bayat, 2007; cited in Myers et al., 2009; Gardiner & Iarocci, 2012). Deveson (2004, p.2) defines resilience as 'the ability to confront adversity and still find hope and meaning in life'.

Resilience comes from an individual’s capacity to maximise the use of available internal and external resources as well as environmental factors such as family and community support systems (Masten, Best & Garmezy, 1990; Rutter & Sroufe, 2000; Waters & Sroufe, 1983; cited in Gardiner and Iarocci, 2012).

Eskow et al. (2011; cited in Gardiner and Iarocci, 2012) indicates that families who receive state medical waiver services in Maryland, USA report more satisfaction with their family quality of life than those on a waiting list, which would mean that family relations, cohesion and functioning could be maintained and improved if family support systems are provided by the state and communities they live in.

Parents found using a holistic approach helped in adapting and coping with their difficulties in raising a child with ASD. Kuhaneck et al. (2010) found that parents who cope and adapt better do this by acquiring more knowledge and skills in raising a child with ASD, and simultaneously, look after their mental, physical and psychological wellbeing. Some parents become involved in volunteer work providing emotional support to others (Smith et al., 2010), in advocating for access and services (Ha et al., 2014; Phelps et al., 2009; Lendenmann, 2010) and by simply being proactive.

2.8. Additional challenges faced by Asian families

It was important to note cultural differences between Western Anglo parents to those living in Asian countries such as China and Vietnam. Asian parents of children with ASD face additional challenges correlated with social and cultural beliefs of their societies. It is a strongly held belief that disability is brought upon an individual as a way of a family’s shame and ‘Karmic demerit’ (Wang et al., 2013; Ghosh & Magana, 2009; Liu, 2005; Luong et al., 2009; cited in Ha et al., 2014) or the disability is contagious to others (Thoresen, 2017). Kormardjaja (2005) cited in Thoresen (2017) indicates people with intellectual disabilities are often the most stigmatised. Negative attitudes have contributed to a lack of services for people.

It is a cultural expectation that the role of the child is to care for the parents in their old age. If you have a child with a disability you will also be responsible for providing the care for that child (Thoresen, 2017)

Further challenges include limited access to assessment and a lack of diagnostic services and well trained professionals, and a lack of government policy and financial support to families dealing with ASD (Tran et al., 2015; Wang et al., 2013; Ha et al., 2014). Mothers who are the main caregivers displayed more psychopathology than fathers (Jeekortok & Chanchalor, 2012; Gau et al., 2012).

2.9. Recommendations from the literature

Counselling and referral services, such as support groups, qualified respite, coping strategies and techniques help families to adjust to living with a child with ASD in both Western and non-Western countries (Corcoran et al., 2015; DePape & Lindsay, 2015; Gardiner & Iarocci, 2012; Gau et al., 2012; Hoogsteen & Woodgate, 2013; Hutton and Caron, 2005; Kuhaneck et al., 2010; Larson, 2010; Lendenmann, 2010; Robert et al., 2015; Smith et al., 2010). It is highly recommended that practitioners working with families have to recognise the universal uniqueness and complexity of parenting a child with ASD, as well as being culturally sensitive to diverse family needs when planning and implementing services (Freeman et al., 2012; Gau et al., 2012; Hoogsteen & Woodgate, 2013; Lendenmann, 2010; Martinez, 2009; Ogston et al., 2011; Phelps et al., 2009; Robert et al., 2015). Working closely with speech pathologists and occupational therapists helps to improve communication, deal with behavioural problems and encourage independent living and is a positive aspect valued by parents (Robert et al., 2015; Larson, 2010; Gau et al., 2012).

Important for Asian families is the need for the provision of appropriate public awareness and education regarding ASD (Ha et al., 2014; Lendenmann, 2010), low cost interventions (Ha et al., 2014) and the support for family advocacy groups (Ha et al., 2014; Lendenmann, 2010; Tran et al., 2015). Efforts on facilitating governmental policy support are crucial in order to increase future possibilities for families and people with ASD to have access to appropriate services (Ha et al., 2014; Tran et al., 2015, Wang et al., 2014).

2.10. Disability context in Laos

In addressing the concerns for Asian parents living with a child with ASD, there is an urgent need to conduct further studies of their 'lived experience'. This current research hopes to identify and support the existing notion of public awareness; increase education on ASD; provide low cost interventions; support families via advocacy groups and empowerment; and to advocate for governmental financial and policy support.

Ha et al. (2014) assert that, although studies on how culture and the social setting influence the understanding and management of autism have increased over the years; most studies conducted have been with families in high income countries. Research conducted in Asian countries including Taiwan (Lin et al., 2008 cited in Ha et al., 2014; Gau et al., 2012), India (Daley, 2004 cited in Ha et al., 2014), Korea (Grinker and Cho, 2013; cited Ha et al., 2014), China (Wang et al., 2013), Indonesia (Santoso et al., 2015), Thailand (Jeekortok & Chanchalor, 2012) and Vietnam (Anh, 2015; Ha et al., 2014; Tran et al., 2015) suggest that ASD is the likely outcome of 'fate'. What remains unresolved from this current literature review is to locate a description of the lived experience of Lao families living with ASD in order to compare and contrast with other countries and find unique differences.

Lao People's Democratic Republic (Lao PDR) is located in South East Asia with an estimated population of about 6.8 million. The capital city is Vientiane. Lao PDR is a land-locked, ethnically diverse and mountainous country (The United Nations in Lao PDR, 2015). Its neighbouring countries include China to the North, Cambodia to the South, Thailand and Myanmar to the West and Vietnam to the East. Lao people living in the low land (60 percent of population) are the largest ethnic group followed by Lao middle land (30 per cent) and Lao highland (10 per cent). The official language is Lao. Theravada Buddhist is the main religion. Lao PDR is a one party socialist republic, which is governed by Lao Revolutionary Party.

Lao PDR has been upgraded to a lower-middle income economy recently, being one the fastest growing economies in the East Asia and the Pacific Region (The World Bank, 2017). However, the performance in reducing poverty has been reported as slow especially in the area of health and education outcomes (The United Nations in Lao PDR, 2015).

The disability sector in Laos is slowly developing, after the ratification of the United Nations Convention on the Rights of People with Disability (UNCRPD) (2006) in 2009, and the current adoption of the Decree on Persons with Disabilities in 2014 (Handicap International, 2016). The National Disability Policy Framework consists of a policy, a strategy and an action plan which is currently being developed by the Laos government in collaboration with international donors and NGOs (Handicap International, 2016).

The current prevalence rate and official data of people with disabilities in Laos is not reliable, with the 2005 National Census estimating only 1.4 per cent of the overall population as living with disability (Handicap International, 2016). The current 2015 National Census has not reported data of people with disability which Lao Statistic Bureau is still working on the data (Handicap International, 2016). This census used six questions from the Washington Group Short Set of Questions on Disability to begin to gather an understanding of the functional difficulties people with disabilities experience (Thoresen, 2017).

Lao PDR does not have an official definition of ASD and this population group was classified under the term ‘intellectual disability’ in the Decree on Persons with Disabilities (Association for Autism (AfA), 2016). The ability to assess and obtain a diagnosis of ASD does not currently exist in the country (Association for Autism, 2016). Families living in Laos have to travel to Thailand to receive a diagnosis of ASD and therapeutic support (Association for Autism, 2016). The assessment visit to Thailand is dependent on the financial resources of families and children require a passport to travel out of the country. Families experiencing financial hardship are unable to access this service. This lack of data, combined with inability to formally diagnose someone with the disorder, means that most people with ASD are essentially invisible.

The only organisation providing support to people with ASD and their families in Laos is the Association for Autism (AfA), a grass-root, not-for-profit association established and run by parents and guardians of children with autism in Laos. AfA was established in 2012 with the ultimate aim of advocating for the rights of people with ASD and their families in Laos to have access to basic education and necessary support services (Association for Autism, 2016).

In terms of culture, Lao people who have ASD are usually considered to be slow developing, strange, aggressive and even stupid or mad (Association for Autism, 2016). Their odd social behaviour often disrupts events or classrooms and makes people feel uncomfortable. As a consequence of these behaviours, individuals are regularly ignored, avoided, excluded and stigmatised (Association for Autism, 2016).

Thoresen (2017) suggests the adoption of ‘the Incheon Strategy has provided specific indicators and reporting recommendations which have allowed organisations to lobby the government to improve services for people with disabilities’.

Laos has been the beneficiary of an Inclusive Education Project from 1993 to 2009 (Save the Children, 2010) which has tried to address many of the inequities in education. Many students in Lao PDR are vulnerable and likely to experience exclusion; girls; children from economically disadvantaged families; children from different ethno-linguistic groups; and children with disabilities. The focus on children with disabilities relates mainly to those with physical impairments caused by unexploded ordnances or those children with visual and hearing impairments. There is little understanding of children with intellectual impairment or ASD.

Historically children in rural areas may only attend school for half a day, not during the rainy season when access is difficult or they may attend incomplete schools that only offer education to Grade 3 (Save the Children, 2010).

Currently there is no training for teachers in Special Education in Lao PDR. The Association for Autism advocates for the need for such courses with the Ministry of Education and Sport. To address the lack of formal training in special education, AfA works continually to develop the skills of its staff through the provision of in house specialist training for its teachers, and sends teachers to Thailand to upgrade their skills (Association for Autism, 2016)

Mainstream teachers have limited training, skills and experience to provide suitable education for children with disabilities in an inclusive setting. Teachers have been known to exclude children with ASD from classrooms because they are perceived to be resistant to learning, naughty, aggressive or disruptive within the class environment (Association for Autism, 2016). This stigma can be extended to their families. Parents have been known to hide their children with ASD or confine them to the house to control their behaviour and hide them from the community. Some children in rural areas may be locked in the home while their parents go to work in the fields. Parents often feel this is a protective way to keep their children safe (Association for Autism, 2016). Adults presenting with 'low-functioning autism' in Laos might be perceived as mentally ill (Association for Autism, 2016). If such adults have not developed basic-life skills they will continue to be highly dependent on families for their entire life (Association for Autism, 2016). Furthermore, if they come from poor families, the lack of social support services in Laos means they could become destitute (Association for Autism, 2016).

It is therefore crucial to learn more about how ASD is viewed within the Lao cultural context; the services that are available; and how Lao families cope with this lifelong condition.

The point of difference is that the experience of Lao families may reflect similarities to and/or differences from other South-East Asian countries due to government, community, education and health resourcing differences. Therefore, this current research project seeks to gain a greater understanding of how ASD affects families in the different cultural context of life in Laos.

2.11. Research questions

Key question:

What is the experience of Lao families who have a child with ASD?

Sub-questions:

1. How does ASD affect families in the different cultural context of life in Laos?

2. What are the experiences in relation to emotional demand, finance, family life, coping and support needed?

2.12. Chapter summary

This chapter has presented a review of the literature on the lived experience of families who have a child with ASD in both Western and non-Western countries. It began by explaining the literature review approach and defining disability and Autism Spectrum Disorder (ASD). The three main findings of the review (1) parents experience of difficult emotions; (2) impact on the family quality of life and (3) coping and adaptation were discussed. The additional challenges Asian families face was outlined along with the main findings on the recommendations from the literature review. The disability context in Laos was discussed and the knowledge gap was identified. The chapter concluded with the aim of this research project which seeks to gain a greater understanding of how ASD affects families in the different cultural context of life in Laos. From this knowledge gap, the research questions upon which this thesis is based have been identified. The next chapter outlines the research methodology by which the data were collected and analysed.

CHAPTER THREE

3. METHODOLOGY

3.1. Introduction

This chapter describes the research design of this current study, including procedures used for managing the collection, analysis and interpretation of the data as well as the methodologies chosen to frame this current study . The design for this research was based on phenomenology in order to reveal the experience of Lao families having a child with ASD. The phenomenological philosophy of Heidegger provides the basis for this current study , which leads to the employment of qualitative methodology of hermeneutic or interpretative phenomenology. This then allows the researcher investigating other Lao families' experience as having lived life rather than conceptualising one (van Manen, 2015). An open-ended survey questionnaire was used to gather Lao families' experience of having a child with ASD. Through careful analysis of the data (the parents' responses), major themes were organised to reveal the meaning of the lived experience of Lao parents having a child with ASD at this point in time.

Parents having a child with ASD who participated in this current study were members of Association for Autism (AfA) in Laos. AfA is a grass-roots, not-for-profit association established and run by parents and guardians of children with autism in Laos. AfA was formally established in 2012 with the ultimate aim of advocating for the rights of people with autism and their families in Laos, to have access to basic education and necessary support services (Association for Autism, 2016). AfA currently has 72 members from five major cities with the majority residing in Vientiane. AfA also governs Vientiane Autism Centre (VAC) established in 2009 as a special education centre providing therapy and educational services to children with autism. VAC is the only centre currently providing services intended to prepare children with autism in Vientiane to join mainstream education (Association for Autism, 2016). There are currently 42 students with ASD aged between 3 to 16 years studying at VAC, among those, 15 students attend the mainstream primary school when VAC's teachers attend with them (Association for Autism, 2016). VAC also trains teachers, parents and others in skills required to support children with autism to reach their potential (Association for Autism, 2016).

3.2. Rationale

While acknowledging the value of Husserl's phenomenology as 'a systematic description of the essential content of our experiences' (Käufer & Chemero, 2015, p.25), this current qualitative research project used the phenomenological philosophy of Heidegger to include the 'interpretative' aspect in order to 'reveal' the lived experiences of Lao families having a child with ASD (van Manen, 2015, p.180). Phenomenology studies are used to reveal the lived experience (Miles, Chapman & Francis, 2015) therefore a qualitative methodology and methods are suitable for the research design and questions. Qualitative methodology allows for a better understanding of the deeper meaning of a family's lived experience as it relates to raising a child with ASD in the context of living in Lao PDR. A quantitative methodology was considered not to be appropriate given the unique nature of each individual parent's experience. Since the focus is on the 'meaning of the lived experience' of Lao parents having a child with ASD (van Manen, 2015, p.62), it cannot simply be explained through a single logical quantitative measurement (Creswell, 2012).

This therefore justifies a qualitative method to investigate and reveal how having a child with ASD affects Lao family life to gain an insight from each parent's experience. Qualitative methodology and methods enable the researcher to 'explore and develop a detailed understanding of a central phenomenon' of various needs of the target groups, such as Lao families who have a child with ASD (Creswell, 2012. p.16). The benefit to the researcher in this current project, therefore, of using qualitative methods based on Heidegger's interpretative phenomenology approach is to reveal the story of being a parent of a child with ASD in Laos as well as making meaning out of that lived experience (Corby, Taggart, & Cousins, 2015; Käufer & Chemero, 2015; Reiners, 2012).

Although the interpretative phenomenological approach contradicts Husserl's 'bracketing' or 'phenomenological reduction' (Corby, Taggart, & Cousins, 2015, p.461), Heidegger's philosophy allows for the acknowledgement of the researcher's previous experience of the phenomenon and accepts this may affect the research interpretation (Corby, Taggart, & Cousins, 2015; Miles, Chapman & Francis, 2015 & van Manen, 2015).

3.3. Phenomenology: An overview

'Phenomenology is the science of phenomena' (van Manen, 2015, p.183). 'At its most basic level, Phenomenology is interested in the study of phenomena' (Vagle, 2014, p.20). The researcher in this current study has sought to understand 'the differences between Husserl's descriptive and Heidegger's interpretive phenomenology' (Reiners, 2012, p.1) in order to guide the most appropriate approach to help answer the research question and in this current study the question is: 'What is the experience of a Lao family having a child with ASD?' The purpose of this study is to reveal the experiences of Lao families having a child with autism spectrum disorder (ASD).

Edmund Husserl (1859-1938) was a philosopher and the philosophy of phenomenology originates from his work (Käufer & Chemero, 2015; Miles, Chapman & Francis, 2015). Husserl believed phenomenology was related to the person's awareness or consciousness of an object or event (Reiners, 2012) and attempts to describe the 'essence' of the experience (Käufer & Chemero, 2015; Reiners, 2012). The experience comes from an individual's awareness received through perception, thought, memory, emotion and imagination of particular object or event (Reiners, 2012). The given immediate experience (phenomena) then becomes the subject of the study being described while setting aside the previous knowledge, perception and thought (Reiners, 2012; Vagle, 2015; van Manen, 2015). Husserl used the term 'bracketing' or 'phenomenological reduction' to explain his belief that phenomenology study should set aside 'pre-conceptions and theoretical notions' (van Manen, 2015, p.184).

Martin Heidegger (1889-1976) was a philosopher who was a student of Husserl and transformed phenomenology to incorporate an interpretative element which is called 'hermeneutics, the philosophy of interpretation' (Miles, Chapman & Francis, 2015; Reiners, 2012). Heidegger adopted the theory of knowledge known as 'ontology, the science of being' (Reiners, 2012, p.2) where he describes how each individual develops relationships with the world in their own ways (van Manen, 2015). Therefore, Heidegger's hermeneutics study is beyond the simple description of the experience but seeks meaning out of it (Reiners, 2012). He described his theory as 'being in the world rather than knowing the world' (Reiners, 2012, p.3). Heidegger acknowledged prior understanding and believed personal awareness of the phenomena was essential to phenomenological research (Miles, Chapman & Francis, 2015; Reiners, 2012; van Manen, 2015). His philosophy stressed that 'the essence of human understanding is hermeneutic, that is, our understanding of the everyday world is derived from our interpretation of it' (Dahlberg, Drew & Nystrom cited in Reiners, 2012, p.3).

Hermeneutic Phenomenology

The main elements of Heidegger's Hermeneutic Phenomenological philosophy include (1) language is the central medium for conveying meaning; (2) the background and socio-cultural context that a given language belongs to are key to understanding the meaning and the possibility of meaning and (3) it is impossible to set aside our knowledge and understanding of the world from our exploration of the phenomena (Altman, Kantrowitz-Gordon & Vandermause, 2014; van Manen, 2015).

Language, interpretation and meaning

In his book *Researching Lived Experience*, van Manen (2015) explained that words alone cannot reach the fullness of describing people's experience. Although people may use the same words to describe a particular situation, there is no guarantee that their subjective felt experiences are the same (van Manen, 2015). The uniqueness of people's inner experience is beyond the linguistic explanation. Therefore, it is important in an attempt to deeply understand the lived experience, the researcher pays attention to both cognitive and non-cognitive aspects of the language (van Manen, 2015).

Van Manen (2015) then identified how language can be used to help researchers make meaning out of participants' experiences through four main elements including:

(1) through the collection of language, the researcher can access experience and find the common themes such as particular insights, concepts and feelings;

(2) through the possible meaning derived from the socio-cultural context that a given language belongs to, as we know that language used in one cultural background is different from another;

(3) through language the researcher discovers the possibility of being and becoming. Language and experience interact with one another. Language helps us explain our experience and through experience we discover words that hold personal meaning to us.

(4) Finding meaning through the non-cognitive language such as feelings on the bodies, our relations with others and how we interact with the things of our world.

After considering these aspects, this research study will use the approach of Heidegger's interpretative phenomenology which allows for the investigation of what is the lived experience of Lao families having a child with ASD. Therefore, the phenomena under examination in this research study, are in the parenting of a child with ASD in the Lao context where the researcher also has the lived experience in similar context and culture. The aim is to tell the story of the particular kind of parenting experience in the Lao cultural context and make meaning out of that experience (see figure 3.1 for an overview of the research methodology).

3.4. Research timeline

The timeline for this research study was one year starting from July 2016 to July 2017. Tasks were divided into five main phases covering: 1) research preparation; 2) data collection; 3) data analysis; 4) data interpretation and 5) project completion. (see Appendix 5: Research Timeline).

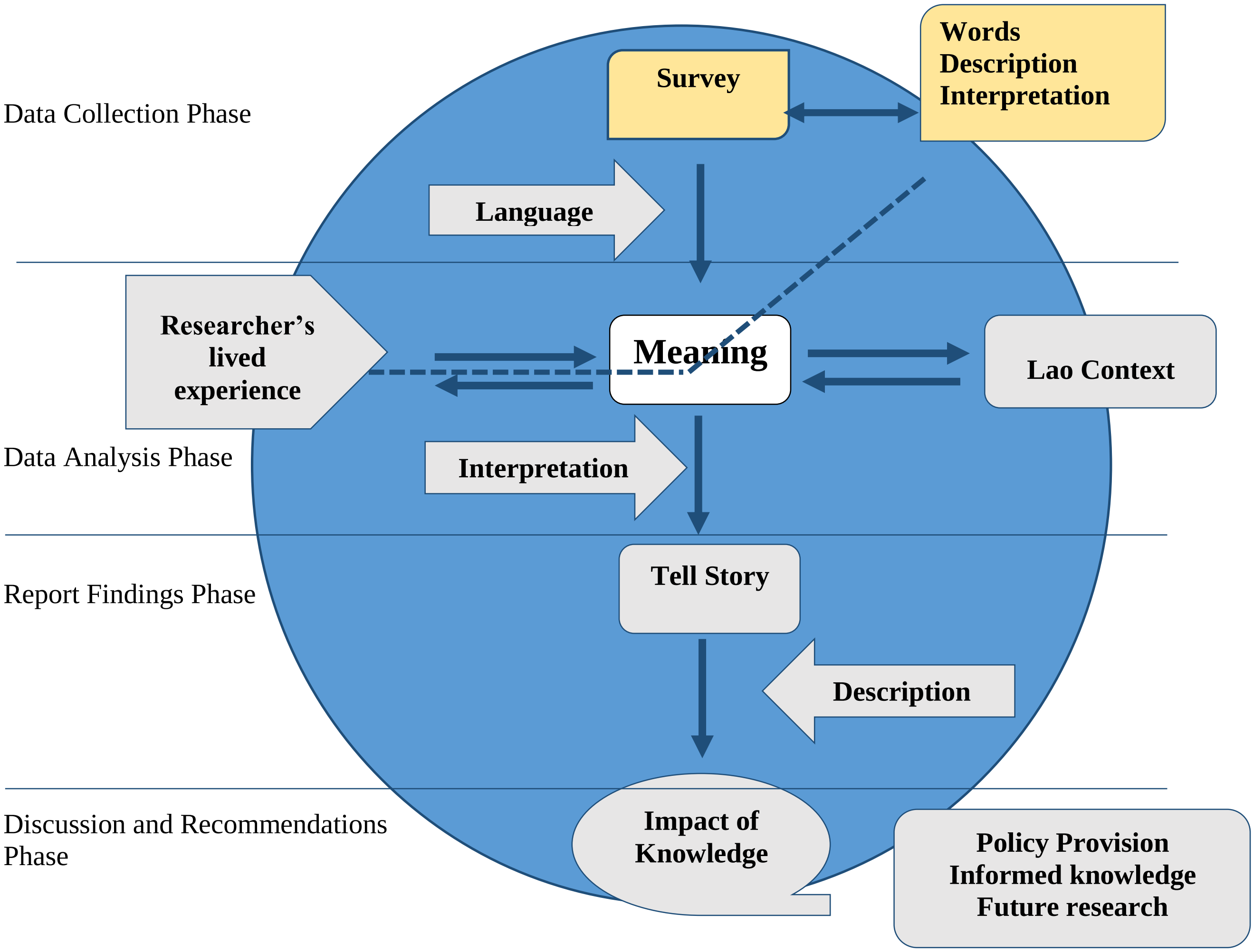

Figure 3.1 an overview of study methodology

3.5. Ethical considerations/Research approval

All research involving human participants is governed by legal requirements and ethical principles (Morgan, Harmon, & Gliner, 2001). Each country has its own requirements and ethical principles. Research must be conducted in an ethical manner in order to safeguard participants and researchers and to make researchers accountable in practice and behaviour (American Educational Research Association, 2011). In this current study , a number of measures were established to ensure ethical considerations and behaviour were maintained all times. As previously mentioned, the researcher in this current study being involved in

AfA was an obvious and noted conflict of interest for the ethics application and subsequent approval. Ethics approval was granted by the Flinders University Social and Behavioural Science Ethics Committee, Project number 7431 in October, 2016 (see Appendix 4).

The key ethical considerations included the recruitment of participants, as there needed to be no perceived coercion in the recruitment process. Consideration was also given to the feelings of the participants, with an action plan in place if the questionnaire stimulated an emotional response. Issues of confidentiality, the nature of voluntary participation, the right to withdraw and the safe storage of the data were considered and explained.

An information sheet was important in the maintenance of ethical considerations (see Appendix 2). Parents were informed that participating in this research project would have no impact on their involvement with AfA and the responses were anonymous. A third party was used as a research intermediary to recruit the participants. The local free counselling service was made available to the parents in case they experienced emotional difficulties as a result of answering the questionnaire. In order to comply with ethical standards, it was important to safely store and retain all data from participants. The survey responses were typed up and saved as a file in the password-protected, locked computer that only the researcher had access to. The original survey responses were stored in a locked filing cabinet at Flinders University.

3.6. Sampling procedure

This current research used purposeful sampling method targeting the population of parents who are members of Association for Autism (AfA) in Laos and who reside in Vientiane Capital. In this current study the term ‘parent’ refers to the primary caregivers of the child with ASD in Laos which may include biological parents, guardians, siblings and carers. Researchers often use purposeful sampling when participants and sites chosen are information rich (Creswell, 2012). Creswell (2012, p.206) explained that ‘in purposeful sampling, researchers intentionally select individuals and sites to learn or understand the central phenomenon’. For this current study , the parents who are members of Association for Autism (AfA) were chosen because their children had formal diagnostic assessment from the hospital in Thailand. Therefore, the study of the experience of these families who have a child with ASD is suitable and sufficient for the purpose of this research.

Since the researcher in this current study was the Co-founder and President of AfA and a current Board Member, there was a perceived conflict of interest in this research project. The conflict of interest was managed through the distribution of the letter of introduction, information sheet and consent form through a non-AfA member. A third party recruiter who has no direct association with AfA, nor any interest in the research outcome was used.

The documentation was translated into Lao and handed to potential participants by the third party recruiter. The documents stated clearly that participation was voluntary with the research purpose being clearly explained. The data collection methods and confidentiality of participants was based on the ethical standards of Flinders University. The participants had the right to withdraw from the research at any time if they wished to. Responses were anonymous and the consent forms were not required by the ethics committee.

3.7. Criteria for participation

Initially this research aimed to receive four to eight returned surveys. The selection criteria included:

- Parents who are members of Association for Autism in Laos;
- Parents living with a child with ASD;
- Parents who live in Vientiane, Laos;
- Parents over 18 years.

Although the consent form was not required by the ethics committee in order to maintain anonymity, the act of completing the survey independently and returning it to Flinders University Supervisor indicated each participant’s acceptance to participate.

3.8. Data collection

The data for this current study are the experiences of Lao parents who have a child with ASD. The method chosen for the collection of the data was a questionnaire using open-ended questions (see Appendix 3). The qualitative questionnaire was used as a research protocol because it helps participants to tell their stories in a reflective manner (van Manen, 2015) without time pressure or being in a face-to-face interaction with the researcher. This was important to manage the perceived potential conflict of interest between participants and the principal researcher. According to van Manen (2015), asking people to write can be an obstacle as people tend to speak more freely than they write. In this case, literacy skills needed to be considered as the questionnaire required participants to describe their experiences covering many life domains. Taking this into consideration, participants were allowed to write in their native language and responses were translated into English by the researcher in this current study, who is fluent in spoken and literate in written Lao.

A further reason for choosing a questionnaire was that culturally, the researcher was aware that Lao people may find it challenging to speak openly about their lives in front of someone they do not fully trust. Criticising or expressing negative emotions in conversation is somewhat taboo in Lao culture. Since this was the first kind of research study conducted with this group of parents in Lao, it is hard to identify an exactly appropriate data collection method at this point in time.

For these reasons, the qualitative questionnaire using open-ended questions was deemed to be the most appropriate data collection method. The researcher aimed to receive some reflective accounts of people's experiences as they answered the questionnaires.

Questionnaire

The questionnaire contained three main parts including instruction, participant general demographic information and open-ended questions that form the basis of the questionnaire (see Appendix 3).

For each open-ended question, participants were provided with some additional prompts supporting them to reflect on a variety of experiences. The open-ended questions were developed from the themes identified in the literature review. Questions included:

1) Please describe your feelings and emotions associated with parenting a child living with autism?
2) Please describe the impact of having a child with autism on your financial circumstances?
3) Please outline the impact of living with a child with autism on your experiences with employment/family/friends/community?
4) Please explain what strategies and supports you use to help you cope in your daily life?
5) What do you believe would be beneficial to enhance your life with a child with autism?
6) Please make any other comments you feel can describe your experience of living with a child with autism?

Data Collection Process

As previously mentioned, a third party was used as a research intermediary to distribute the information package and questionnaires. The information package included both the English and Lao version of the Letter of Introduction (see Appendix 1), Information Sheet (see Appendix 2), Questionnaire (see Appendix 3) and the return envelopes. The English version of the package was submitted to the Flindera University Ethic Committee. After ethics approval, the researcher checked the translation accuracy and posted 65 copies of the package to the research intermediary in Laos.

Packages (n=15) were distributed at the AfA Annual Meeting on 17th December 2016 by the research intermediary who was provided with a verbal script in Lao language. The script provided the research intermediary with the relevant information for recruitment of the participants to the study. During the following week, information packages (n=30) were also distributed at Vientiane Autism Centre at school pick up and drop off time. A total of 45 packages were distributed.

Participants were given the options to return their response by email to the Flinders University Supervisor or place it anonymously in the collection box at AfA to be posted at the same time. Two questionnaires were returned by email. A further 24 were returned via the AfA collection box. A total of 26 completed questionnaires were received.

Recruitment Overview	**Total members**
Total AfA members (by child)	72
AfA members in Vientiane Capital	65
Number of AfA members provided with information package	45
Number of returned questionnaires	26 Response rate 57%

3.9. Data Analysis

Data was analysed using a content analysis methods in responding to the large number of returned questionnaires (Creswell, 2012; Elo & Kyngäs, 2007; Hsieh & Shannon, 2005) while acknowledging that thematic analysis is the most common form of analysis in phenomenological qualitative research (Creswell, 2012).

Content analysis was employed to allow the researcher to systematically describe and quantify the phenomena (Elo & Kyngäs, 2007). It opens the researcher up to being guided by data rather than the prior knowledge of the phenomenon (Hsieh & Shannon, 2005). Content analysis can be used with either qualitative or quantitative data based on the purpose of the study and is useful when literature and theory regarding the phenomenon is limited. In this case, little is known about the lived experience of Lao families having a child with ASD. Under this process researchers are expected to immerse themselves into the data in order to gain complete insight (Hsieh & Shannon, 2005). The main approach of content analysis is to come up with categories that are derived from the analysis of the data from specific to general (Elo & Kyngäs, 2007). The lived experience of each participant is observed and combined into a larger whole to help the researcher look for meanings, intentions, consequences and context (Downe-Wamboldt, 1992 cited in Elo & Kyngäs, 2007).

Data Analysis Process

The data analysis process started with the translation of survey responses from Lao to English followed by the verification of the translation and manually conducting content analysis of the data. Since the survey response rate (n=26, 57%) more than tripled the initial estimated response rate (n=8), the principal researcher formed a translation team using three Australia Awards students from Laos to help with the translation. The researcher then proof read all the translations to ensure accuracy and consistency of the words used. The support of initial translation of the survey responses by Lao students has helped the principal researcher to overcome emotional difficulties experienced while reading the survey responses in original language due to the similarity, to that of respondents, of the researcher's lived experience. The journal of the researcher's emotional experiences was kept as a tool to help the researcher separate her own assumptions from the facts.

The university supervisor approved the cancellation of the translation verification process using the certified translation company in Laos due to the large numbers of survey responses, time constraints and cost of verifying service. This allowed the researcher to continue analysing and organising the qualitative data after the full immersion into the data during the translation and proofreading phrase.

Although there are no systematic rules for analysing data using content analysis, the principal researcher followed three main steps identified by Elo & Kyngäs (2007) on the qualitative content analysis process. An explanation of each step is made below:

1) Selecting unit of analysis

The whole description of experience (words) of each participant was the unit of analysis under this study. Then the researcher used six questions in the questionnaire as the main cluster to start with. The benefit of using the whole survey response as a unit of analysis was that it helped the researcher capture the key message of the story each participant wanted to tell before grouping them into categories later in the process.

2) Immersion in the data

This process is about getting to know the stories (Berger & Lorenz, 2016) and striving to make sense of the whole data by reading through the data several times (Elo & Kyngäs, 2007). This process is particularly important in this current study due to the researcher sharing the lived experience with the participants. It is crucial to separate the participants 'truth from the researcher's assumption' (Berger & Lorenz, 2016). The translation and the proof reading of the participants' survey response is a useful step in immersing in the raw data. The researcher in this current study recorded her own initial thoughts about the process to clearly separate her own feelings and experiences out of the stories told by the participants. The researcher also asked the translation team to report on their first impressions after the translation, in order to capture the whole meaning.

Question 3	**Code**	**Mother/Father/Carer**	**Answers from participant**	**Preliminary Data Analysis**	**Researcher's reflection**
Please outline the impact of living with a child with autism on your experiences with employment/family/friends/community	1		.		
	2				
	3				

Figure 3.2: Preliminary Data Analysis Table

3) Organise the qualitative data

The researcher then used a spreadsheet to record participants' answers to each of the questions in one column, preliminary data analysis in another column and the researcher's reflection in a separate column (see sample table as shown in Figure 3.2).

The researcher read the answers from each participant under each question which was the main cluster and wrote notes and headings in the preliminary data analysis column. The researcher wrote her opinions, ideas, feelings and experiences in the researcher's reflection column.

The researcher then created categories by classifying data into a particular group of meaning (Elo & Kyngäs, 2007). The categories formed the basis to describe the phenomena, increase understanding and generate knowledge (Elo & Kyngäs, 2007). Under this process, the researcher interpreted the meaning of the data and decided which statements to put in the same category (Elo & Kyngäs, 2007). For this current analysis, the researcher noticed both positive and negative themes experienced across many participants' descriptions and decided to use positive and negative themes as the main categories.

The phrases that participants chose to describe their experiences were then classified under positive and negative column. The researcher added the score column next to both positive and negative themes in order to record the frequency of similar phrases and words used by total participants. Phrases and words that received the highest score then formed the basis of a common theme that the researcher then assigned meaning to. The researcher then sought the validation of categories, themes and clusters with the university supervisors and an academic tutor (see Figure 3.3: Sample Table of Creating Categories).

Positive Theme	**Score**		**Negative Theme**	**Score**	
Easier when going to the place with less people	1	going out side	have to look after the child very closely when going out/difficulty going outside	9	Going out side
Easier when going out to familiar places	1	going out side	Child lack of communication strategies/ non-verbal	3	Child factor
Not much difficulty when going out because family understand the child	1	going out side	Child does not aware of dangerous/keep minding	2	Child factor
Raising a child with ASD is not too difficult	1	General statement on experience	Social discrimination saying that special need child is stupid and need discipline	2	Social discrimination
The child severity level is less	1	Child factor	Society lack of knowledge and understand and blame parenting style as making the child naughty/	8	Society lack of Knowledge & understanding
Child has some communication strategies	1	Child factor	Family friendship and community involvement is less /Limited opportunity for parents to go out with friends/less opportunity to travel/visit relative	7	General statement on experience
Child able to follow some instruction	1	Child factor	Raising a child with ASD requires a lot of attention	3	General statement on experience
Not much behaviour when going out	1	Child factor	Raising a child with ASD make life holistically difficult/very difficult/used to be very difficult/impact many areas	8	General statement on experience
Impact within the family or outside is not much because Father own a business and willing to do his best to support the child	1	Parent factor	Very tiring	2	Feeling
Parent has to take lead explaining about autism in the society (advocate)	2	Parent factor	Require patience	2	Feeling

Figure 3.3: Sample Table of Creating Categories

The researcher then used the step called ‘abstraction’ where she formulated a general description of the lived experience through identifying main categories and sub categories (Elo & Kyngäs, 2007, p.111). Subcategories with similar events and incidents were grouped together as one main category using the name that reflected the characteristic of the content (Elo & Kyngäs, 2007). In this current study, the researcher extracted the content from Table A into a smaller and more precise content in Table B as shown in Figure 3.4: Sample Table of Abstraction.

The thematic analysis process was also used to validate the analysis and help the researcher connect the themes displaying sequence, causes and effects of how having a child with ASD impact the Lao parents in different life domains.

Table A

Impact on employment	
Negative Themes:	n/18
Impact on work attendance such as, take leave often to look after the child/ leave early and arrive late at work due to the morning routine takes long time	16
The impact is quite high/It is difficult to explain to others at work place	7
Cannot accept work that require traveling away from home due to the responsibility of the child	4
Less concentration and motivation at work/performance is not as good	3
Cannot accept work with high responsibility because the child need is always a priority/difficult to move up in a career	3
Cannot balance working and spending time with the child/feel sick, stress and under pressure	3
Do not have much chance to socialise with colleges after work/join organisation events	3
Positive Themes:	n/18
There is not much impact We own business	2

Table B

Cluster (3.1): Impact on employment	
Negative Themes:	n/18
Impact on work attendance	16
Impact on performance and career development	14
Difficulty finding balance between work and demand for child care	9
Positive Themes:	n/18
There is not much impact	2

Figure 3.4: Sample Table of Abstraction

3.10. Study Rigour

To ensure the rigour and validation of this current study, the researcher and the university supervisors paid attention to principles of qualitative inquiry and ensuring that verification was carried out throughout the whole process of research design and implementation (Morse et al., 2002). Extensive discussion and consultation were undertaken between the principal researcher and university supervisors during the literature review, formulation of research questions, and approach to the methodology, data collection and analysis.

The following table describes how the researcher maintained the rigour of the study using the framework identified in Morse et al. (2002) and aspects of trustworthiness identified in an Elo and Kyngäs (2007) study.

Research viewpoint	**How it is addressed in this research**
Credibility	▪ Peer debriefing and validation of research methodology and methods from university supervisors and academic tutor. ▪ Validation of clusters, themes and categories with university supervisors and academic tutor to ensure that it reflects the data; ▪ Prolonged engagement with the data through translation from Lao to English; proofread and discussed the first impression with translation team.
Transferability	▪ Clearly identify criteria for participants; ▪ Explain reasons for choosing participants as Lao parents having a child with ASD in the data collection section; ▪ In-depth description of the process of data collection and data analysis.
Dependability	▪ In-depth description of research methods; ▪ Demonstrate a link between the results and the data; ▪ Describing the analysing process while reporting the results; ▪ Use of citations to help readers link the categories with the original data; ▪ Provide sample table of how data was analysed in the section of data analysis process.
Confirmability	▪ Survey responses will be stored securely if it is needed for future reference; ▪ Content analysis conducted using the guideline of inductive approach described in the peer-review journal article of Elo & Kyngäs (2007).
Auditability	▪ Provide logical research timeline; ▪ Data can be traced through data collection, analysis and discussion.
Reflexivity	▪ The position of the researcher is clearly stated; ▪ The acknowledgment of the research lived experience is made available; ▪ The process of ensuring the separation of the researcher's assumptions and the participants' truth is explained in the data analysis process.

The use of qualitative questionnaires as the research protocol in this current study provided an in-depth reflection of participants' experience which form the rich and quality data for the researcher to work on. The immersion into the data during the translation and proofreading process provided the strong foundation for the researcher to understand the data.

3.11. Strengths and limitations of the method

A significant strength of the current study was the high response rate of Lao parents who have a child with ASD and their willingness to share their experiences. A writing task required answering questionnaires did not stop parents from providing quality accounts of their lives. Since this current study is aimed at revealing the experience of Lao families having a child with ASD, having the key stakeholders such as parents share their experience was a key strength underpinning the credibility of the data. The richness of data also derived from the large sample size confirmed the dependability of the study. The literature review also provided a good foundation and insight for the need for this study to be conducted in Laos.

Another strength was that the researcher has a lived experience of having a child with ASD, having lived life in the Lao context as well as the Australian context. The understanding of the meaning of the language used in the original written accounts as well as its context is very important in the interpretation and analysis of the data. The researcher noted the difference in accuracy and deeper meaning of the translation of the survey responses of the Lao students who do not have any relevant background or knowledge in the field. Therefore, having shared experience with the participants helped the researcher connect with the written text as if she was talking to the participants face-to-face. As a result, the researcher experienced emotional difficulties during the translation process and had to seek support from the counselling service to move forward.

A research intermediary was used to reduce the face-to-face interactions between the principal researcher and the participants. The inclusion of the researcher’s name in the recruitment material may have introduced a power imbalance and the participants may have felt pressured to present a positive note when talking about the AfA and VAC.

It should be noted that this current research was conducted using people who were receiving some services from AfA. The results may not be generalised to represent the whole population, however there may be elements which are transferrable to parents of children with other types of disability. The results can only be interpreted in context as the opinion of this group of parents of a child with a disability.

3.12. Chapter summary

This chapter has described the use of the phenomenological approach to this current research as well as the rationale for using qualitative research. A qualitative questionnaire using open-ended questions was the method used for collecting data. The data was then analysed using a combination of thematic and content analysis techniques and process. Participant selection criteria, ethical considerations, strengths and limitations of the study design were also presented. The following chapter will present the findings relating to the lived experience of Lao families having a child with ASD.

CHAPTER FOUR

4. FINDINGS

4.1. Introduction

This chapter presents the key findings of the open-ended survey responses from 26 parents, three caregivers and a sibling of children with ASD in Laos. The survey questions asked participants to describe their experiences in six main areas of 1) feelings and emotions associated with raising a child with ASD; 2) the impact of having a child with ASD on financial circumstances; 3) the impact of having a child with ASD on participants' employment, family relationships, friendships and community involvement; 4) what are some of the strategies and supports families used to help them cope with their daily life; 5) what would be beneficial to enhance participants' lives living with a child with ASD; and 6) other experiences that the respondents may want to share. All original responses were in Lao language. The responses were translated into English by the researcher, who is fluent in spoken Lao and literate in written Lao, and three Lao students studying at Flinders University. The researcher proofread the translations to ensure accuracy and consistency of wording used. Themes and subthemes were formed accordingly.

4.2. Length of responses

All questions were open-ended and parents were free to write as much or as little as they felt comfortable to write. Two parents' responses were very brief, i.e. between 20-66 words answering only demographic questions and two questions describing feelings and financial impact. Most parents answered all six questions. Twelve parents wrote between 200-500 words. Seven parents' responses were between 550-896 words. Five parents described their experiences in detail using more than 1000 words. The longest answer was 1626 words, which was equivalent to five pages.

4.3. Characteristics of participants

There were a total 26 respondents; 12 fathers, 10 mothers, 3 carers and one sibling of a child with ASD living in Laos who participated in this current study (see Table 4.1). Half the participants were aged between 40 to 50 years old, nine were between 29 to 39 years old and four were younger, aged between 18 to 28 years old. Although the scope of this current study was aimed at only those who lived in Vientiane, there were two families from the southern province of Laos (Champasak) who voluntarily sent their survey answers to Flinders University. All participants were members of Association for Autism in Laos (AfA) and two held additional roles as board members of the organisation.

Of the participants, 70 per cent (n=18) self-reported as having low income, where they earned less than the average GNI of US$ 1,740 in 2015 (The World Bank, 2017) [1]. Twelve families (Mother (2), Sibling (3), Mother (4), Father (7), Father (8), Father (10), Carer (12), Mother (16), Father (21), Father (22), Father (25), and Father (26)) reported earning between 3,010,000 to 8,000,000 LAK (Lao Kip) per month which was equivalent to about US$ 366-985. Six families had a very low income (Carer (5), Father (13), Mother (14), Carer (15), Father (18) and Father (23)), earning less than 3,000,000 LAK which was equivalent to about US$ 363 per month.

Four families [Mother (17), Mother (19), Mother (20), Father (24)] considered themselves as being close to middle income earning status where they earned between 8,010,000 to 13,000,000 LAK which was equivalent to about US$ 986-1584 per month. Only two families [Father (6) and Mother (9)] were considered as coming from a middle income background earning more than 23,010,000 LAK, equivalent to about US$ 2830 per month. Two families [Mother (1) and Mother (11)] chose not to disclose their income status.

Participants Number code	Role in the family	Age Bracket	Income per Month (Lao Kip)	Role in AfA	Location
(1)	Mother	40 – 50	Not specified	Member	Vientiane

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[1] Lao PDR's income categorization has been upgraded from a low income economy to a lower-middle income economy by The World Bank in 2011 with the average gross national income (GNI) per capita in 2015 of US$ 1,740 (The World Bank, 2017). Lower-middle income economies are those with average incomes of US$ 1,006 to US$ 3,975 (The World Bank, 2017).

(2)	Mother	29 – 39	Between 3,010,000 – 8,000,000	Member	Vientiane
(3)	Sibling	18-28	Between 3,010,000 – 8,000,000	Volunteer	Vientiane
(4)	Mother	29 – 39	Between 3,010,000 – 8,000,000	Member	Vientiane
(5)	Carer	18 – 28	Below 3,000,000	Member	Vientiane
(6)	Father	29-39	Over 23,010,000	Member	Vientiane
(7)	Father	40-50	Between 3,010,000 – 8,000,000	Member	Vientiane
(8)	Father	40-50	Between 3,010,000 – 8,000,000	Member	Vientiane
(9)	Mother	40-50	Over 23,010,000	Member	Vientiane
(10)	Father	29-39	Between 3,010,000 – 8,000,000	Member	Champasak
(11)	Mother	18-28	None	Member	Vientiane
(12)	Carer	18-28	Between 3,010,000 – 8,000,000	Member	Other
(13)	Father	40-50	Below 3,000,000	Member	Vientiane
(14)	Mother	29-39	Below 3,000,000	Member	Vientiane
(15)	Carer	29-39	Below 3,000,000	Member	Vientiane
(16)	Mother	29-39	Between 3,010,000 – 8,000,000	Member & Board Committee	Vientiane
(17)	Mother	40-50	Between 8,010,000 – 13,000,000	Member	Vientiane
(18)	Father	40-50	Below 3,000,000	Member	Vientiane
(19)	Mother	40-50	Between 8,010,000 – 13,000,000	Member	Vientiane
(20)	Mother	40-50	Between 8,010,000 – 13,000,000	Member & Board Committee	Vientiane
(21)	Father	40-50	Between 3,010,000 – 8,000,000	Member	Vientiane
(22)	Father	29-39	Between 3,010,000 – 8,000,000	Member	Vientiane
(23)	Father	40-50	Below 3,000,000	Member	Vientiane
(24)	Father	40-50	Between 8,010,000 – 13,000,000	Member	Vientiane
(25)	Father	29-39	Between 3,010,000 – 8,000,000	Member	Champasak
(26)	Father	40-50	Between 3,010,000 – 8,000,000	Member	Vientiane

Table 4.1 Participant Demographics

4.4. Overall findings

Three major themes are presented, each inclusive of five subthemes which were derived from the thematic and content analyses (see Figure 4.1). Lao families who participated in this current study of living with a child with ASD reported experiencing challenges across a range of major life domains such as emotional wellbeing, finances, family relationships, employment, friendship and community involvement. While this group of parents reported struggling to find the right balance in life raising a child with ASD in the community with the limited support options, their experiences revealed a great deal of resilience. Participants' overall reflection of their journeys confirmed that positive adaptation was possible when supportive relationships within and outside the family existed. Both positive and negative elements existed in the overall experiences of Lao families having a child with ASD. Although there were more negative elements than positive, it was also clear that families have strong ideas of what supports and approaches have been helpful and what would be needed to enhance their lives and that of their children into the future.

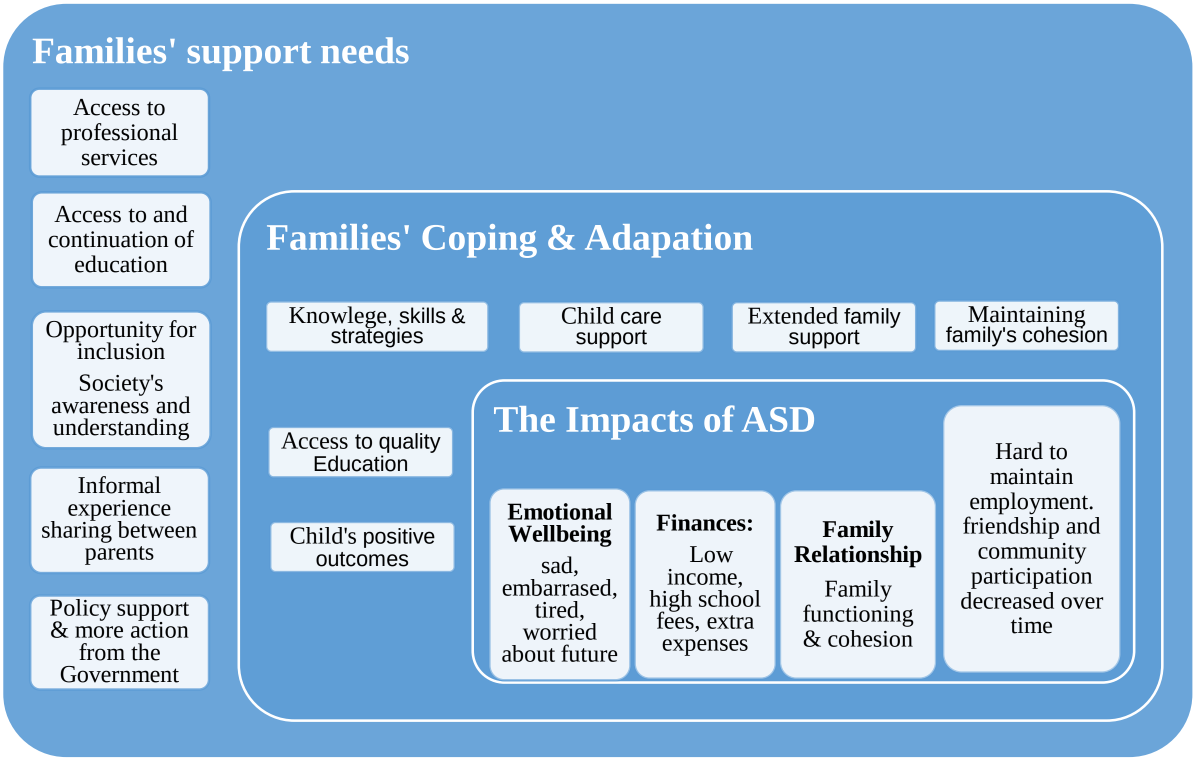

Figure 4.1 Themes derived from the data

4.4.1. ***The impacts of ASD***. Within this theme parents described how having a child with ASD impacted family life in all major life domains which included emotional wellbeing, financial circumstances, family relationships, employment, friendships, and community involvement.

4.4.2. ***Families' coping and adaptation***. This theme revealed parents self-reported supports and the strategies families used to help them cope, which included strategies that benefit the families and those that benefit the child with ASD.

4.4.3. ***Families' support needs.*** This theme explained a combination of supports that families identified that enhanced their life living with a child with ASD. The subthemes were ranked in prioritised order derived from parents' accounts namely, having access to professional services, access to and continuation of their child's education, having opportunity for inclusion, having more opportunity for information sharing sessions with other parents who have a child with autism and the call for more policy support and action from the government.

4.4.4. Families' overall reflection of their journey. This final part summed up the holistic view of the participants' experience from their own accounts where they focussed more on the key factors that contributed to the positive adaptation.

4.5. The impacts of ASD

4.5.1. Impact on emotional wellbeing (Life Domain 1)

The vast majority of participants (n=25) experienced a variety of feelings and emotions. Although the overall tone was more negative, the majority of parents (84%) shared a mixture of negative and positive feelings and emotions associated with raising a child with ASD (see Table 4.2). One father (6) wrote: *'The feeling of having an autistic child is mixed between disappointed and proud'*. Many participants spoke about the various negative feelings of sadness, disappointment and embarrassment during the initial period of diagnosis, a mother (19) shared '*When knowing that my child has autism, I felt disappointed and anxious'*. A mother (9) explained the feelings of denial, embarrassment and hopelessness during the diagnostic period due to the lack of knowledge about the condition and how to handle it as well as the '*pressure from the family, relative and society. I felt embarrassed when taking him out with me'*.

Emotional Wellbeing	**n/25**
Mixed feelings both negative and positive	n/21

*	***Negative feelings:***	
	Sad, disappointed and embarrassed	19
	Worry about the child’s future	16
	Tired with the high support needs, difficult, hopeless	15
	Discouraged that the ASD child cannot enjoy the same life	12
*	***Positive feelings:***	
	Happy, proud, encouraged when seeing the child progress	16
	Acceptance, feeling empathy for the child, love and want to do the best to help	9
Negative Feelings only:		**n/4**
	Shock, unhappy, stress and severely depressed	4

Table 4.2 Impact of having a child with ASD on family’s emotional wellbeing

Some respondents talked about their worries about the child’s future and not knowing how to help as one mother (4) expressed her worry about the child’s future *‘I was not sure how he was going to live his life and play like other children*’, and father (13) wrote: ‘*When realising that my child has autism, I worry a lot about my child on how to help him to live independently’.*

More than half of the participants expressed difficult emotions and tiredness associated with the daily support needs of the ASD child as one mother (11) wrote: *‘I have to involve in everything. It is tiring and hopeless’.* Another spoke about difficulties related to behaviours of concern as one mother (20) wrote: *‘I am so tired both physically and mentally. There are many times that my child escape from home. Many times that he go up the roof of the house’*. Some participants spoke about feeling discouraged and experiencing inequity, one father (23) summed this up clearly:

‘Sometimes I feel sad, sorry, depressed, hopeless that she has this condition because I see other children can go to mainstream school, play and be happy with friends while my girl is about the same age but cannot enjoy the same life’.

Despite going through various negative feelings, these participants also reported experiencing positive moments where 64 per cent spoke about feeling happy, proud and encouraged when seeing the child’s positive outcomes. One mother (19) expressed joy in her child’s ability and progress: *‘I feel happier and prouder that my child has a positive progress and I never think before that he would be able to improve like this’*. Some parents specifically talked about the benefits and changes that happened in their life after having more knowledge about ASD. Parents benefited from learning practical skills to work with their child which allowed them to see the child's improvement. One mother (20) wrote about how having skills helped her child to improve and enriched her wellbeing as *'I am happy that we have Vientiane Autism Centre. I am happy that I learn skills to teach my child. The day that I teach him and he listens to me and follows me, I feel very happy, which I cannot explain in words'*. Another mother (9) wrote that *'after I found out that I can train my child and learn some of the technique and saw my child made good progress, I felt hopeful, relief and now I felt happy'.*

A few participants described feelings of happiness, love and pride in the way that they learned to accept the child for who he/she is and see their ASD child as no different from other children in the way that they bring love, smiles and happiness into the family. One carer (5) wrote that *'sometime he makes me smile, laugh and happy the same way as other children do'.* One mother (17) described in detail her son showing affection through *'hugging, kissing'* and staying close to her brought peace and happiness to her. She felt proud every time he accomplished tasks and these small achievements encouraged her to love and care for him more.

Some participants specially described the importance of acceptance within the family unit and called for acceptance in a broader context such as with relatives, friends and society as a way to help them move forward. One mother (11) wrote about her experience of learning to accept and staying positive: *'Although it is difficult, I like to remind myself about positive. I have to learn to accept and look after them to my best'*. A father (26) also called for acceptance in the community as he continued his account: '*I want society to be aware of this condition and give children with autism an opportunity, not look down on them, accept and understand them'*. One mother (9) expressed her determination to move forward as *'I felt ... confident to take my child out in the society despite sometime people still do not understand and not give opportunity …. I do not feel embarrassed anymore. I am positive …. I feel encouraged to keep fighting'*.

Participants also spoke about their positive feelings of empathy: '*I also feel empathy for my child*', reported father (10); love; and willingness to do what it takes to help their ASD children. One mother (4) wrote about her happiness in seeing her child play with friends and confirmed the love and attention that the family had for the child reporting that *'now I feel a lot better as I can see him able to play with friends. Our family pay good attention to him and love him more'.* Father (13) also expressed his positive feelings and determination for the child: *'I am proud of my child and love him more and willing to do all I can for him'.*

A small group of participants described only negative feelings and emotions during the diagnostic stage when they did not have any knowledge about ASD as being *'shock'* expressed by father (8), with feelings of unhappiness, stress and severe depression. One father (25) explained his stress: *'After knowing that my child has autism ... the happiness time is very limited .... I ... cannot sleep well, always worry ... with my child every day'.* Similarly, mother (16) wrote about the overwhelming nature of her negative feelings and how it led to severe depression: '*My feeling at that time include worry, anxious, sad, confused and embarrassed. I also feel sorry for my child and did not know what to do. Sometimes I even thought about suicide, family, sibling did not understand'.* One father (21) told that '*I am not happy with my life raising a child with autism'.* This father could only see the negative side of ASD which he described his child as being '*self-centre, not listening and very naughty'.*

It is clear that parents' lack of education about ASD and strategies to work with their children are the main cause of the negative feelings and emotions and that seeing the positive outcomes of the child is the main source of parents' hope and encouragement.

4.5.2. Impact on financial circumstances (Life Domain 2)

Some participants (n=24) expressed that having a child with ASD affected family financial circumstances in many ways. School fees were regularly mentioned as being a major expense for families; for many the school fee at VAC took more than half of the family income, leaving little for other household expenses. One father (25) shared details of the impact of the school fees before and after the diagnosis:

> *'Before the diagnosis of autism, the school fee for my child was 80,000 LAK per month. After the diagnosis of the delay and autism, my child joined Vientiane Autism Centre, the school fee is very high which is 2,200,000 LAK per month. I am the only income earner in the family'*

The impact on financial circumstances of having a child with ASD, n=24 responses		
*	School fee is high (Vientiane Autism Centre)	15
*	The financial impact is high on low income families	11
*	Raising a child with ASD incurs extra spending	11
*	Being the primary carer limits opportunities for income earning	7
*	Financial assistance provides a relief for families but does not alleviate the challenges	3
*	The financial impact is low	1

Table 4.3 The impact on financial circumstances of having a child with ASD

Other participants explained the difficulties of sending the ASD child to public school as a cheaper option. One mother (17) stated that '[Public] *School cannot provide appropriate education. Therefore, ... we also have to look for schools or institution that we believe will be able to help our child'*. With exclusion and poor quality of education for children with ASD in Vientiane, families have little choice but to access high cost education, as one father (26) explained: *'Having a child with autism highly impact our financial circumstances because they require special educator and equipment to help them learn'*. Some families wanted the ASD child to access mainstream education, but to do so they had to pay an extra fee for the opportunity with no guarantee of the quality, as one sibling (3) wrote *'The school fee is double because it is harder to look after them at mainstream school. The school charge more from parents. Some schools refuse them as they do not know how to handle the behaviour'*.

Participants with low income reported the financial impact associated with raising a child with ASD as being very significant for their families; one single income earner and another who was a government officer receiving a salary that was less than the expenses for the ASD child alone, not to mention other household expenses such as, food, electricity, water and other utilities. One father (13) wrote: *'Being a government officer receive little salary. Fees associated with raising a child with autism and providing education to him is higher than my salary'*. Another father (18) stated that *'father's income is less than the child's school fee'*. Some identified specifically that expenses related to the ASD child's education and support consume the majority of family income as one father (22) explained: *'The expenses related to our child is about 80 per cent of our overall family income'*.

For some families the expenses expanded to providing support for other extended family members living in the same house, which limits their ability to set aside some money for saving in case of emergency. Father (25) explained this situation very clearly: *'There are seven members in the family that I responsible for. Each month I hardly have any money left for saving. I have to pay other fees related to my child and diagnosis fee as well'*. Another mother (4) wrote about their financial difficulties of raising two children with special needs while also being responsible for the older family members:

> '*I have a lot of problem on financial side because our family income is not much. We have to pay school fee for our 2 children with special needs and we have to look after the elders as well. Both of us are government official'*.

Regardless of the income status, participants wanted their sons and daughters to receive quality and appropriate education and support. They insisted on sending the child to Vientiane Autism Centre and travelled to Thailand to get proper assessment and diagnosis even though the cost involved put a huge strain on their financial circumstances. One mother (14) summarised the situation:

> *'I want him to receive appropriate care and support to help him learn and grow. The problem is I have low income but I still insisted to bring my child to the centre. There are other costs related to the activities participation as well which affect my financial situation so bad. I sometime cannot pay the school fee on time and cannot clear the family's related bills'*.

Half of the participants expressed that raising a child with ASD incurred extra spending. Participants spoke about the spending related to the regular travel required to Thailand to receive assessment and diagnosis, therapy services and doctors' appointments, which cost them a lot. One father (26) wrote *'There are many cost involve starting with assessment and diagnostic that include the travel cost which is quite high'.* Another father (10) who lives in another province of Laos explained the additional cost related to travelling to receive therapy within the country as well: '*Sometimes I travel to Vientiane for him to attend VAC which I had to take leave from work and paid for all the travel related expenses'.* The extra spending also relates to the cost of buying and upgrading learning materials and extra support paid to teachers and therapists. Some participants stated the cost associated with taking their ASD child to participate in community activities was also high. One mother (9) summed up her extra spending:

> *'We also have to spend more on specific learning materials for him. There are also travel cost to take him to see professional in oversea and take him to travel very often as part of exposure to the society and community'.*

Other participants described the extra spending on food, as one sibling (3) described: *'We also spend more money on his food as he only eat certain food'.* Father (7) stated that '*raising a child with autism is difficult and incurs high expenses such as on school fee, travelling to see doctor and food related'.*

More than a quarter of participants shared that being a primary carer limits their opportunities for income earning. One mother (19) wrote: *'I cannot fully participate in work because I have to give time to my child'.* Some explained about becoming a single income family due to the demand for care; as father (10) explained: '*The mother has to quit her job in order to look after the child. Since then, our family finance has been highly impacted'.* Participants also explained the need to earn additional income in order to cover all expenses as mother (17) expressed:

'The child's school fee is more than half of the salary. At a result, we have to find an alternative ways in order to earn more income that can be enough to send him to school for his education and development'.

A small number of participants explained the feeling of relief through receiving the financial assistance from the Association for Autism as one mother (1) said: '*Parents have financial responsibility for every children and family … the difference is that the school fee for a child with autism is higher. For low-income families is quite complicated. Luckily we received financial assistance.'* One father (21) wrote that '*having a child with autism, we have to pay high fee for school compared with other children. Luckily, we receive some financial assistance from the Association to help cover some of the school fee'.* However, for other families there are other challenges as one mother (11) wrote: *'Although we received some financial assistance from AfA, it is still hard for us because apart from school fee we have other expenses in the family'.*

Out of 24 participants who provided financial information, only one high-income earner said that the impact on family finance was not high. However, they acknowledged that extra money was required for supporting the development of children with ASD. This father (6) wrote: *'Raising a child with autism incurs some amount of finances but it is also ways to help them improve. Our family understand that we need to spend a lot of money to help our child so the impact on financial to us is not that high'.*

It is clear that raising a child with ASD has significant financial impact on families. Families are unable to access full time employment due to the higher need for individualised care of the child (they have limited working hours or one parent needs to give up work) yet they have higher expenses in order to gain education and opportunities for their child.

4.5.3. Impact on family relationships (Life Domain 3)

All parent participants (n=22) described how raising a child with ASD affects their family relationship both negatively and positively. Many parents (n=15) reported negative emotions associated with the high demand for care of the ASD child and how limited knowledge and understanding of ASD affected family functioning and cohesion. Some parents used the word ‘stress’ to describe their emotions. Mother (9) reported that *‘family members experience high stress’*. For others stress was inherent in their answers. Parents spoke of the marital strain; the challenges they face as the child grows, the non-compliance behaviour and dependency of the child affected the functioning of their family life. One father (13) described the impact of sharing the childcare roles between a husband and wife: *‘We got home very tired from work but still have to pay special attention to the child …. Sometimes we leave it to our partner to handle and our partner want us to handle’*. Another father (10) explained the conflict caused by the feeling of strain and the misunderstanding between him and his wife about balancing the ASD childcare demands and being a single-income family.

Other family members felt annoyed, angry and frustrated with the child’s limited communication and behaviours which resulted in arguments. As father (23) wrote: ‘W*e sometimes had a fight due to this’*. Some parents stated they had arguments due to their limited knowledge and understanding about the cause of ASD as one mother (11) wrote: *‘Parents still did not understand what is happening to our child and we sometimes have argument and not understand each other. We tend to blame that we did not parent correctly or spoiled him too much’*. It is clear that the stress associated with the high demand for care can affect the family’s harmony.

Personal time together as a couple was limited as most of their time was spent devoted to the child with ASD, which put further strains on the relationship. One mother (20) wrote *‘parents do not have time for one another and becoming the usual practice. We do not ask the feeling of each other’*. Another mother (9) explained that *‘we do not have much time to care for our partner’s feeling and vice versa because our child issues always keep us occupied’*.

On the contrary, a few families acknowledged the difficulties but also felt empathy for the child and tried to do their best; as father (10) expressed: *‘In fact our family relationship* *improves because of having a child with ASD and because of our love to the child that unite us'*.

Another father (25) wrote:

> *'Overall, the happiness moment is very limited. However, my wife and I understand each other and try to face this difficulty in life. We want to find all solution that will help our child to improve. We think that when our child improve and happy, we will also be happy'*

A number of parents (n=7) talked about their family dynamics experiencing positive change based on a number of factors such as paying special attention to family relationships and understanding. Mother (1) reported that *'everyone in the family will help each other'*. Father (6) asserted that *'our family will not allow autism to impact our relationship. We must keep our understanding of each other'*. The love and empathy for the child as well as trying to understand their behaviour were also identified as factors that brought about positive adjustment as mother (19) wrote: *'Everyone love him, feel empathy for him and his needs always come first'*. A carer (15) told us that *'the aunty and uncle help us look after the child, try to understand his behaviour and also help with school drop off and pick up and they love our child'*. Families adapted better when they had a shared vision and clarity in roles and responsibilities.

4.5.4. Impact on employment (Life Domain 4)

The impact on employment was mostly negative. Most parents (n=18) described how the lack of child care support and the need for constant supervision of the child were the main factors limiting their ability to be fully engaged in employment, affecting their work attendance and ability to find a positive work/life balance. One mother (11) reported that '*if I cannot find anyone to mind my child, I have to take him to work with me. I don't have focus to do my work because … I have to look after him all the time including feeding him, take him to toilet and everything I have to be involved. So I can't work. This is the main difficulty'*. Carer (15) described the impact on her performance and career development: '*We missed the opportunity to attend other work related training to improve our* *performance because we cannot leave our child alone'*. Mother (9) talked about having to choose between time for the child or earning: *'Father who is the head of the family has to quit his job in order to help me … spend more time with him'*. Father (25) talked about the exhaustion around finding work/life balance and how it affected his career development:

> *'Yes very high … put me under pressure because my career development decreased …. Travelling back and forth cause a delay .... Every organisation wants a good and hardworking employee … a good leader who can balance the work and family demand well …. I cannot do it because many times my physical health is so tiring. It is hard to explain to others and make them understand'*.

Some parents talked about the need to take leave from work often due to the lack of child care support during the school holiday or when the child was sick. Father (21) reported that *'when the centre closes I have to take work leave to look after my child at home'*. Father (23) *explained that 'when school break, I cannot bring her to my work place because she is always moving around, noisy, therefore I have to take a day off from work too in order to take care of her at home'*. One carer (12) wrote about her lack of employment: *'If I do not have a career I cannot go to work. He needs a full time care'*.

A few participants (n=3) indicated that the impact was not high, sharing that things such as flexible working hours, owning their own business and having access to after school hours care were ways which reduced the impact of ASD on their family. It was a choice these families made, a luxury which many low income earners may not have. *Father* (26) described the situation: *'Sometimes, I have a lot of work and cannot pick up my child on time and the centre has to charge for overtime. But I have to choose to complete my work because if there is no work I have no money'*.

4.5.5. Impact on friendships (Life Domain 5)

The majority of parents (n=18) reported their friendships reduced as a result of having a child with ASD. Parents identified the negative attitude others had about ASD (n=11) and the demands in caring for a child with ASD (n=7) as the reason their friendships were reduced. Parents spoke about feeling hurt and embarrassed by the way some friends labelled the child and judged both the child and parent; carer (15) wrote: *'My friend often asked what was happening to him: "Can't he speak?" "Is he insane; mental retard?" When these questions were asked, it hits my heart directly'*. Carer (5) explained how people's attitudes toward her child made her feel: *'I feel embarrassed and sad …. Some of them laugh at our child and some feel annoyed with the child because the child likes to move a lot and not sit still'.*

Parents stated some friends openly disliked their ASD child; criticised their parenting style; and did not reach out for them anymore. Mother (9) wrote: '*Some friends do not understand my child. They often speak behind us inappropriately …. Some other friends do not contact us too, so the connection and friendship become less'.* Another father (21) talked about some friends who lack understanding about ASD and did not keep in touch: *'They think that my child is very naughty and do not want to come to my house'.* Father (26) explained about feeling reluctant to continue the friendship with some friends who discriminate against their child:

> *'Some friends criticised us that we follow our child lead too much. Some friends … do not want our child to play with their children and do not want our child to go to their house because they afraid that their children will copy our child behaviour … I feel that they did not like my child'.*

A few parents took the lead in explaining ASD to friends, advocating for their child and then chose to remain friends with only those who have a non-judgemental attitude toward persons with ASD. Father (6) stated that *'friends has to understand not to judge friendship by having a child with ASD'*. Another father (8) wrote: *'We have to be the one who explain to them that autistic child is a child. They only have their ways expressing their feeling differently'*. Sibling (3) shared they were left with fewer, but stronger friendships as a result of having a child with ASD in the family: '*We ended up having less friends but good ones with understanding of our family circumstances'*.

Some parents spoke about the reduction of their friendships due to the time required to provide constant care for their child. Father (25) wrote: *'My friends and I do not have much* *chance to meet or even to talk on the phone …. Friendship is very important and I always have it but it has to reduce because of the change in our family circumstances of having a child with autism'*. Another father (22) explained that he *'did not have much time to keep in touch with friends'*. Some participant especially spoke about the constant supervision while going to friends' homes; as mother (17) explained:

> *'It is rarely for me to participate any activity with friends …. If I can join, I have to take my son with me which most of my time I have to stay with him in order to be sure that he will not hit other kids or destroy other peoples' stuff'.*

Only one mother (11) reported feeling gratitude of having understanding friends who provide emotional support. She further explained that her friends' families also have kind attitudes reaching out to her and her son and making them felt welcome. She wrote:

> *'The impact on friendship is not high because I am lucky to have understanding friends. When my friends have party, I can bring my child with me and everybody in my friends' family were very welcoming. They provide emotional support to me all the time'.*

4.5.6. Impact on community involvement (Life Domain 6)

Almost all parents (n=22) reported that their participation in the community was limited due to having a child with ASD, due to the difficulties with the child's condition, including behaviours of concern and the need for constant supervision. Some talked about society's lack of understanding that made them feel reluctant to take the child out. A few families found some coping techniques for maintaining community outreach by using the child's emotional clues as a signal for alternative actions as well as balancing caring role and socialisation between couples. Only one parent reported that the impact on their community involvement was minimal.

Many parents described the inability to fully participate in activities due to the constant supervision required and concern for the child's safety when participating in activities outside the home. One mother (9) explained that *'I cannot fully participate with others because I have to run after my child. I feel tired and bored'*. Another mother (14) reported that, *'my child cannot sit still. So I missed out the social events'.* One father (26) explained his difficulties in many areas: *'When participate in community event or activity, my child cannot understand the rules and we cannot fully integrate because I have to ensure his safety around the place'.* Opportunities for both parents joining events together was limited; as one father (21) wrote: *'My wife and I have to take turn'.* This was further supported by father (10) who said:

> *'It is difficult to attend community functions because we have to look after the child. We can't leave them too long, we feel worry. Therefore, we end up not joining activities such as the village cleaning day, the village meeting, Buddhist related event, wedding. It is not easy to bring the child to those event with us'.*

Some participants spoke about the difficulties associated with their ASD child's limited communication, self-care skills and behaviour as one carer (15) expressed: *'He will reach out and take whatever he wants. He sometime not following instruction in group activities. We will have difficulty with eating, going out and go to toilet'.* Another mother (1) wrote: *'If he has to do some new activities, he will get upset and cry'.* One father (22) wrote broadly about his limitation, saying that he *'cannot go out much because my child is different'.* Another father (23) described his child's behaviour when bored:

> *'My child did not cooperate in activities ... she is not interested in. She made loud noise. She moved around a lot'.*

Others simply explained the impact being that they cannot participate in activities that they used to; here the experience of limitation was inherent in their answers: *'I cannot take my son to places that I feel not appropriate',* reported father (6). *'I cannot participate in any activities that I used to',* reported father (25); and *'I do not have much time to participate in the community or social event',* explained father (13).

Parents talked about difficult feelings saying that they felt *'uncomfortable and embarrassed about having an autistic child',*(Carer 12), and '*I am afraid that people will feel annoyed*', (Mother 9), resulting from the lack of understanding in society. Some described the barriers to community participation when they referred to society's lack of understanding. As father (7) wrote: *'It is difficult because society still don't know much* *and accept it yet'*. Another father (23) accounted: *'Other people look at us as strange people so we have to take her home'*. One mother (16) stated that *'many people don't know and understand about autism so I rarely join community activities because it is not easy to do so'*.

Two families wrote positively about their experiences of community involvement as they had a coping strategy of removal from activities once they noticed the child having difficulty: *'We will observe our children if they start to feel uncomfortable then we will take them home and remove them from the activities'*, *(*Mother 4). Another family balanced the caring role and socialisation by either husband or wife going the event alone; as father (21) wrote: *'For joining social event, my wife and I have to take turn. If I go, she has to stay home looking after the child and if she goes, then I do the same'.* Only one mother (11) stated that having a child with ASD did not have much impact on her community participation due to the child's ability to follow instructions in different environments: *'The impact on community is not much because my child is able to listen to the instruction both at school, out of school and at home'.*

4.5.7. Summary of the overall impact of having a child with ASD on participants' employment, family relationships, friendships and community involvement

The general impact of raising a child with ASD on employment, family relationships, friendships and community involvement of a number of participants (n=23) were classified into three main themes; (1) the experience is negative (n=11); (2) the experience is mixed between positive and negative (n=9) and (3) the experience is positive (n=3). Participants identified three main causes of the negative experiences as being the high demand for care; lack of understanding and acceptance of ASD in society and the lack of childcare support. As a result, parents experienced a variety of difficult feelings and emotions, their family functioning and work attendance were impacted as well as their friendship and community involvement became limited and decreased over time (see Figure 4.2).

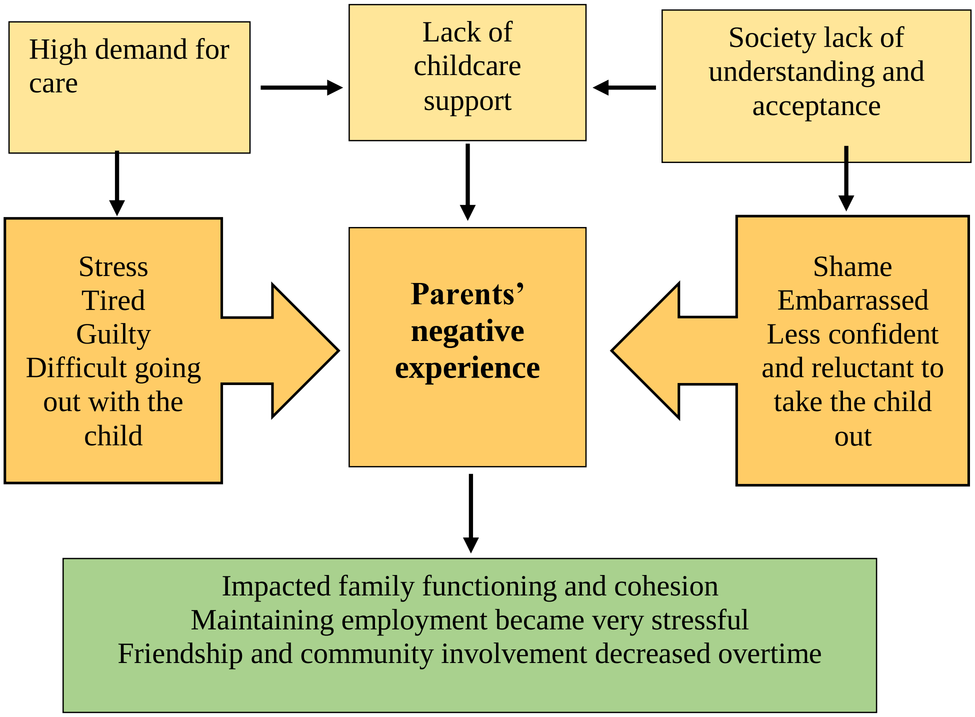

Figure 4.2 The relationship between factors that cause negative experiences

Despite the difficulties, some participants identified sources of positive experiences that come from the love and understanding of the child, their value of community participation and the understanding from family, friends, workplace and community (see figure 4.3). Participants spoke of their initiatives to explain ASD to the community; as father (8) wrote: *'We as a parent have to explain so that people understand'*. Likewise, father (10) insisted on taking the child out to educate the community: *'Having a child with autism should not be a shame …. I always take my child to different social events'*. Many talked about the importance of participating in activities as written by one mother (14) that *'It is very difficult because my child cannot sit still and has limited attention … but it is important that he has opportunity to go out'*. Another carer (15) said that *'it is quite hard when we take him out to community event but we still take him out'*. Father (13) acknowledged the importance of love and explained that *'he likes to us to follow his lead, hug and kiss him. Therefore, we should not shout at or hit them'*. Some participants spoke about workplace understanding as one father (22) wrote: *'Luckily that my work place understand my situation'*. Another mother (16) explained the increase in knowledge of people around her:

> *'Before, raising a child with autism is very difficult. It impacted family members, relative, work and friends because family and society did not aware and understand …. I have to take leave very often from my work. I had very limited opportunity to go out with friends because they do not understand my child. However, currently my family and people around have better understanding'.*

A few participants (n=3) who found the experience positive spoke about fewer difficulties going to places outside home as they understood the child's need well and the child had less issues with communication and behaviour. One mother (4) explained *'We do not have much difficulties when going out because we understand our children well and we will go to places that we know',* another carer (5) wrote about the reduced demand for care associated with the child condition and behaviour:

> *'Raising a child with autism is not too difficult for us. It depends on the severity …. She can communicate with us. She can follow instruction. She is quite good at controlling herself when she is outdoor with us …. She doesn't have tantrum often'.*

Father (6) wrote that ASD did not have a widespread impact on their family due to the family owning their own business. This father reported coming from a middle-income status where he earned more than US$ 2800 per month. Owning a business and earning a stable income could provide both the flexibility in working hours and the sense of financial security. These two factors have been identified by other parents as being the positive aspects in raising a child with ASD.

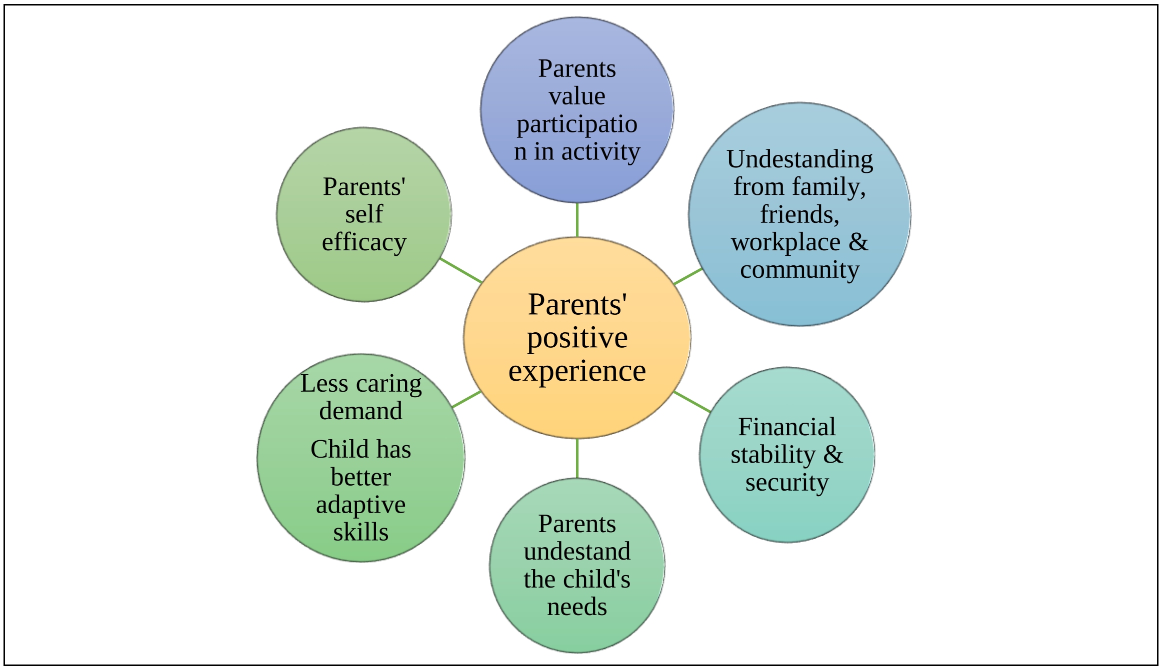

Figure 4.3 Factors contributing to parents' positive experiences of raising a child with ASD

4.6. Families' coping and adaptation

Under this theme, participants were asked to share the strategies and supports they used in order to help them cope with parenting a child with ASD. The support options available to this group of participants having a child with ASD in Laos were limited. The available support can be classified into two categories, the informal support network (family unit, extended family and friends) and the formal support network (the school, teachers, financial assistance and professionals in Thailand). More than half of the participants (n=14) used a combination of both informal and formal supports while some remaining participants (n=9) only described using informal support. Immediate family members supporting one another and working collaboratively with the Vientiane Autism Centre (VAC) were regularly mentioned in the parents' accounts (see figure 4.4).

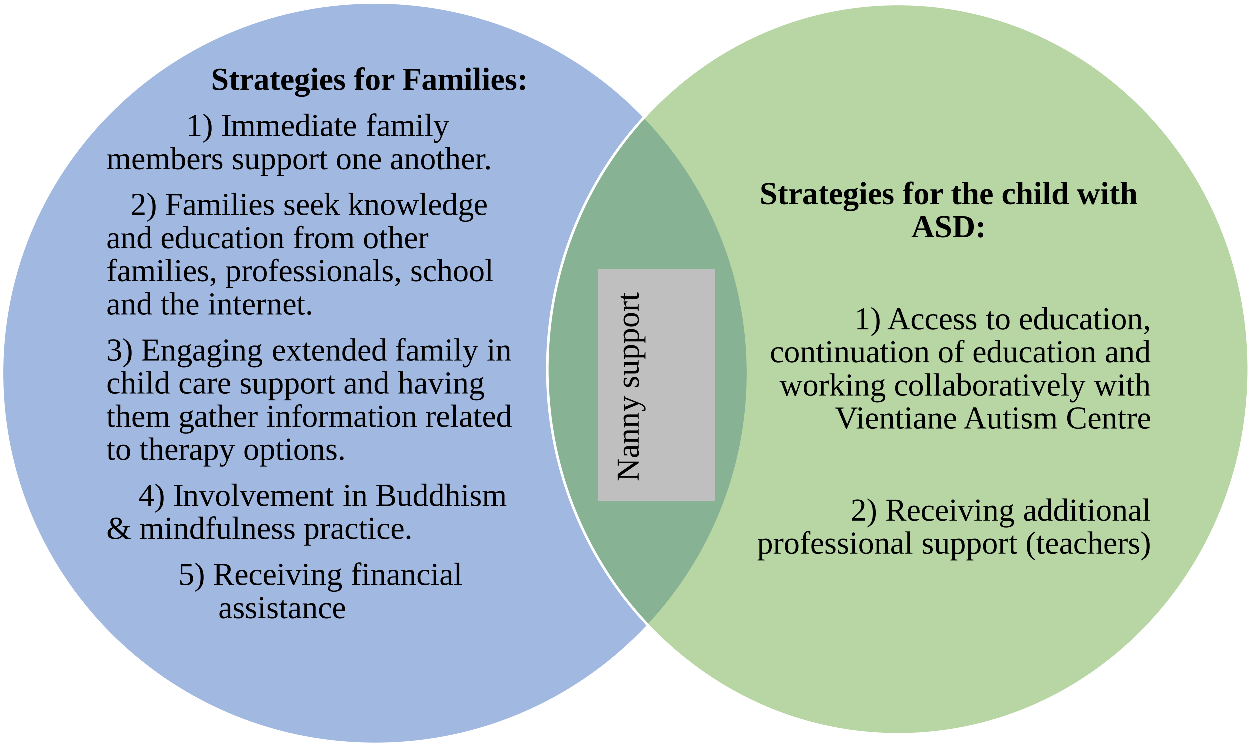

Figure 4.4 Strategies used by parents both for themselves and for the child with ASD

Parents (n=11) spoke about the importance of immediate family members supporting them to care for and to teach the child with ASD daily living skills, social skills and to help to involve them in the community. Father (6) wrote: *'Our coping strategies of daily living is to help each other in order to help the ASD child to live independently. We devote about one hour or 30 minutes every day to help each other'*. Another mother (4) stated that *'family is important to help and support one another'*, and father (10) reported that *'our family put on hard effort to support our child for a better development'*. While many families identify as having family members supporting them as the key strategy, one family found it hard to do so which caused them stress. Father (25) shared this clearly: *'I talked to my two brothers* [who lived in the same house] *asking them to behave better and increase help and involvement and interaction with our boy who has autism. But the result is not as good as expected'*. Without the immediate family members supporting each other it was difficult to maintain family cohesion.

Another useful strategy for families (n=7) was to seek knowledge about ASD. Some travelled to the neighbouring country of Thailand in order to acquire knowledge from other parents, professionals and organisations due to the lack of information available in Laos. Some found the internet was a useful tool to help them understand more about ASD. Others spoke of the benefits of the informal sharing of experiences between parents who have a child with ASD. One mother (9) expressed her gratitude for learning from others in a similar situation, sharing that *'we learnt from other parents' experiences and adjust the technique to suit our circumstances'*.

Using the support from extended family members was one of the coping strategies families (n=5) identified as being helpful. Carer (15) discussed the value of her parents' and sister's assistance providing childcare and explained that she has seen the improvement in her child as a result. Mother (17) explained that extended family members helped her by seeking out information about therapy options for her child.

One family (mother 9) acknowledged their involvement in religious activities, specifically Buddhism, helped them to maintain positive wellbeing. The action of taking the child to the temple for prayer and worship supported the family to feel *'calm'* and *'mindful'*.

Three families tried employing a nanny for support in the home. However, these experiences varied in success. One mother (1) had some help from a nanny while the parents attended work prior to the child starting school; at this young age the assistance of a nanny was useful. Two families reported that having a nanny provided more challenges than benefits. Father (25) explained their negative experience with a nanny who was unable to engage with the child so gave the child the phone unattended in order to keep them occupied which resulted in more behavioural problems for the child. Sibling (3) stated that *'sometimes we leave the child with others who do not understand my brother's communication difficulties* [which then] *caused behaviour of concern.'* If the nanny does not have adequate skills then it may result in more stress for the family. On the other hand, one family (mother 19) described the success of hiring a skilled teacher to teach her son at their home after school hours. However, this was not sustainable due to the expense and a reduced income.

Three families acknowledged the barriers that make it challenging for them to adapt to life with a child with ASD. One father (26) described a number of challenges

> '*There is not much support from society or organisation or government especially the awareness of the impact of raising a child with autism is limited. The general school and teachers still not accept a child with autism in their schools and cannot accept their behaviours. I think in Laos there are only a few schools that accept children with autism to be included in their schools'*.

Father (25) acknowledged there is limited support and understanding of ASD in the community and suggested the need for policies and financial support for single income families. Father (18) supported this by saying that receiving financial support has been of benefit to his family.

A significant number of parents (n=11) identified access to education, continuation of education and working collaboratively with VAC as one of the main strategies to help their children. One carer (5) expressed her gratitude that her child had access to VAC and where the child was able to make progress. She explained that VAC provided both childcare support and education and was the only support her child was currently receiving. Father (26) reflected on the value his family place on education stating that they made great effort to earn enough income to pay for the school fees and other related expenses required for the child. Father (22) explained how his family worked collaboratively with VAC by using the Individual Education Program (IEP) as a guideline to work with the child at home. Father (13) described his family coping as *'We currently work in collaboration with VAC on how to support and teach our child especially on the daily living skills'*. It is clear having access to the right support and education benefited both families and the child with ASD.

All the strategies that benefit the families will ultimately benefit the child with ASD because the families' wellbeing will be improved. With the right support and knowledge and positive wellbeing, the family will be empowered to continue improving the outcomes for their children with ASD and the family as a whole.

4.7. Families' support needs

Under this theme, families shared what supports they believed were needed in order to enhance their experience of living with a child with ASD. While the vast majority of parents (n=19) identified a list of various supports they needed to enhance their lives, some (n=5) only wished for the opportunity for their child to access professional support services and that their family members continue to support one another. Parents reported seeking supports that would bring the best possible outcomes for their child with ASD and expressed the need for a combination of supporting elements. Having access to professional support services, education and the opportunity for their children with ASD to experience inclusion were the top three supports on the participants' wish list. Many participants valued the support within their family unit and the informal experience of sharing with other parents and teachers. Some hoped for a qualified respite service, while others stressed the need for support and action from the government. A few discussed about the barriers they were experiencing. Some spoke about the child's access to basic public health services and others talked of the need for more service providers (see figure 4.5).

Figure 4.5 below provides a summary of the variety of supports that parents believed would enhance their lives and bring positive outcomes to their children with ASD and the family as a whole. Although the supports are classified either to benefit more the child with ASD or the family, they are interconnected. The positive outcomes for the child provide hope and encouragement for the family and the family's empowerment and positive wellbeing provides a strong foundation for the child with ASD to experience the good things in life.

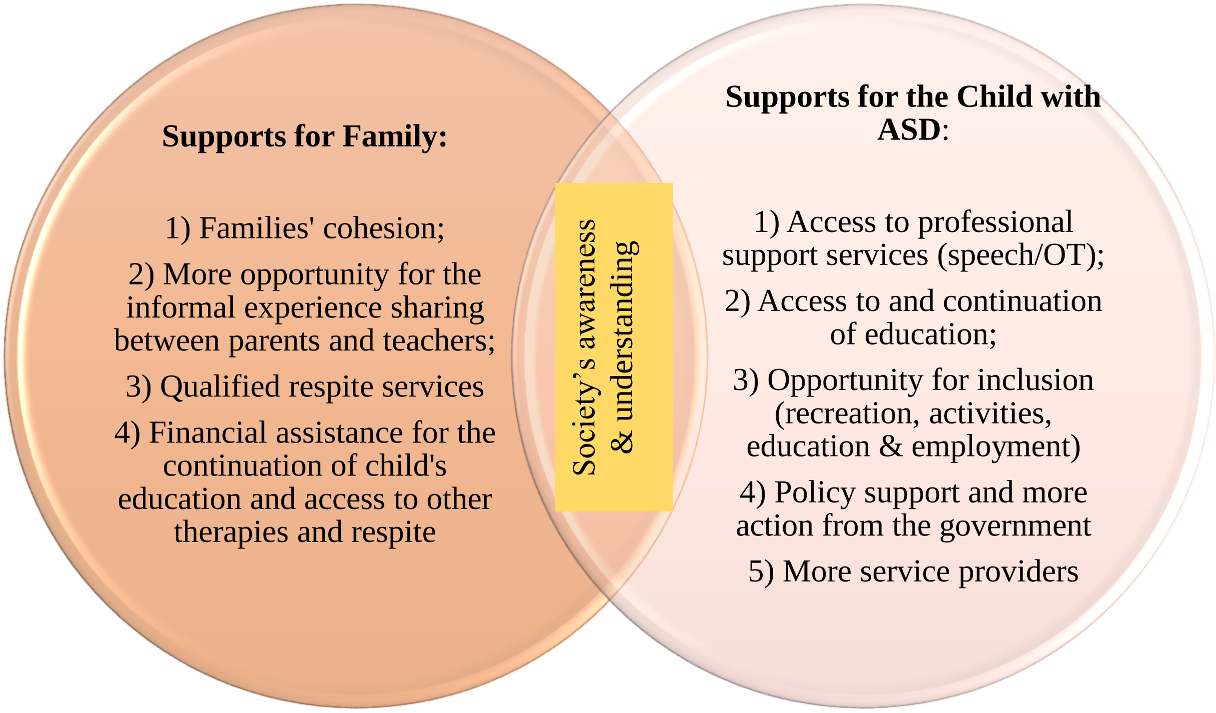

Figure 4.5 Support needs that families identified

Seventeen parents who identified having access to professional support services as a pressing need, spoke about the importance of speech and communication for the child; the right information about therapy options; child progress assessment; and capacity building for parents. Carer (5) expressed clearly her desire for the child with ASD to be able to communicate and speak as well as to process information faster. She wanted to work with speech and occupational therapists. Father (21) explained that he would value speech and communication support and the need for speech and occupational therapies, since '*receiving professional services such as from speech therapist, occupational therapist and others would help enhance our life and our child development if he can speak and communicate'*. Father (22) believed having access to professional services would help speed up the development of his child *'I am willing to be tired if it is going to help my child to develop. I want to receive professional services in all area in order to help my child to develop faster'*. Father (10) indicated the importance of receiving professional evaluation of his child's developmental progress while the father (25) wanted to have access to the right information: *'Receiving the right information from professionals or from AfA on the* *techniques and how to look after and help our child would be very helpful'*. Another father (26) explained about his desire to learn and apply different techniques by working with the professionals *'to help foster his child's development'*. This reflects the need for professional services that can work alongside the families identifying appropriate strategies and modelling the application those strategies to the families.

Thirteen parents spoke about access to and continuation of education in different areas according to their child's and the family's needs. Carer (15) explained the importance of education that aimed to improve her child's *'daily living skills such as eating, mobility, bathing and toileting'*. She also valued the opportunity to learn in an inclusive environment, which would help improve her child's social and academic skills in the area of complying with the classroom rules, participating in activities with friends and learning to write. Mother (4) focused on a broader picture of skills need for her child' expressing her desire for *'more curriculum on independent living skill'*. Carer (12) wrote *'Elements that are important to me include: 1) access to education is very important because it will foster the child development.'* Some families talked about ensuring the continuation of education in order to maintain developmental progress, together with the importance of community participation and inclusion. Father (18) stated *'There are many elements that will enhance our life such as the continuation of education and regular participation in different activities'*. This reflects the importance of an individualised support program that considers and incorporates the person with ASD and his/her family's needs with an underlying emphasis on education.

Other families discussed more support options to be made available through having more service providers. Sibling (3) wrote:
'I want to see more organisations provide help to an ASD child'. Father (8) stated: *'I also want to see more support from organisations working in this field to continue helping us so that our child can learn to be independent in the society'*.

Seven parents discussed the opportunity of their son or daughter to experience inclusion in different ways. Father (7) spoke about the importance of society's awareness and understanding as an opportunity for his child to join in activities. Mother (16) hoped to see her child living a good life by having a job that he enjoyed doing. Mother (19) raised her concern about her child being uncooperative when going to the hospital and suggested that providing education in this area by inviting doctors and nurses to come to the centre would be beneficial. A few parents (mother 9, father 18) expressed they valued participation in recreation and community activities for their child. It is clear parents wanted to see their children live a normal life and only asked for the basic rights that other citizens have access to such as education, healthcare, employment opportunities, recreation and access to public facilities.

Five participants valued the support within their family unit. Father (26) wrote about the need for cohesion in the family stating that *'family has to work together to help the child'*. Father (6) reported that family members supporting one another in looking after the child with ASD was an important part in enhancing his family's life. Father (25) expressed that the understanding and help from his other family members in household chores as well as providing childcare when parents were away helped him experience a positive life. For the sibling (3) having a positive life also meant seeing other family members become a better person as the result of having a child with ASD in the family, as she wrote in her account:

> *'The best part of having him is that my ASD brother inspires my older brother who used to drink a lot and do nothing become a better person. My older brother stop behaving in a non-productive way due to his understanding of our family difficulties and we help each other'*

More opportunity to informally share the experience with other parents of children with ASD as well as teachers was identified by five families as being helpful. Father (13) explained the importance of regular parent and teacher meetings to agree on the learning goals and to give and receive feedback to ensure the best possible outcomes for the child. Carer (12) summed this up as *'Participating in activities with other parents is very helpful because it gives opportunity to share experiences and also provide platform for better interaction between adults and children'*.

Five families stressed the importance of policy support and more actions from the government to help eliminate some of the barriers to education, acceptance and community inclusion. Father (10) who reported having a low-income status living in the southern province of Laos described his difficulties due to the lack of alternate education, public facilities and government support:

> *'Currently the existing social activities that is autism friendly is limited. We don't have autism centre in the province which is a big problem. I think the government should pay more attention on this support process to children with ASD. Because a lot of activities involves with government offices. And if the government provide some supports, it will take some of the load out of the parent and we could do a better job parenting our child'.*

Mother (9) stated seeing concrete actions from the government such as, having the Law on Disability clearly define the supports available; ASD education made available at the University and the hospitals; having special education teachers in the country and seeing the public school capable of handling the child with ASD would bring a positive change to family life *'These would bring more hope and encouragement for us as a parent to continue living and supporting our child happily'*. Other parents asked for financial support to cover the child's education and hospital staff who were capable of providing services to their children. Mother (20) wrote *'I want my autistic child to receive financial support from the government on education and health care'*. Carer (15) confirmed the need: *'There should be more services to autistic people at the hospitals because it is hard to find place to take care of our child when he is sick'*. Mother (19) wrote: *'He missed the public health services that make available through mainstream school. Plus, he does not cooperate when going to hospital'*. Mother (16) spoke about her priority need being financial assistance for her child's school fees and mother (14) expressed her inability to afford professional services that were necessary for her child.

A few mothers spoke about needing qualified respite and support to access the service. Mother (17) stressed the need for a qualified respite service to allow parents some rest from being the primary care giver for the child with ASD and dealing with the behaviour issues in order to maintain their wellbeing. Mother (11) acknowledged her needs for time away but could not afford to hire a carer therefore; she also wanted support to access a respite service. It is clear these families have been struggling on their own for quite some time and they are in real need of supports beyond their capacity and control, which need to come from the public sector.

4.8. Families' reflection of their overall journey

Parents reflected more on positive aspects of their life journey from diagnosis, acceptance, adaptation and moving forward. Internal and external factors associated with the positive adaptation were identified and reported by parents participating in this current study. Love, understanding, devotion, patience and acceptance were regularly mentioned by these parents. Families having knowledge and strategies to deal with their child's behaviour and communication difficulties were also discussed as one of the internal factors contributing to building each family's resilience. Receiving support from VAC and seeing the positive outcomes of the child were identified as providing hope and feeling of gratitude toward lives. Some indicated the need for external support from society.

Eight parents spoke about the inner qualities required to raise a child with ASD positively. Love and understanding were the foundation for patience, acceptance and positive outcomes for both parents and the child with ASD. Mother (9) wrote: '*The most important aspect of raising a child with autism is that parents have to have the love and understanding of the child. Love and understanding will help us become more patience and forbearance'*. Father (10) described his love for the child with ASD as a source of his *'courage to fight with pride'* by taking his child to different places fighting with the feeling of shame and explaining about ASD in his work place. This commitment brought more empathy from his colleagues and made him feel proud. Father (23) expressed his positive attitude toward life as:

> *'Raising a child with ASD require a lot of devotion and patient as well as emotional strength when facing challenging situation. We have to have the hope that our child will develop although others may say that there is no point to teach them'.*

It is clear that parents experienced and accepted the challenges associated with raising a child with ASD but their love of the child and their resilience had helped them to move forward and face the adversity with wisdom.

Five parents spoke specifically about receiving support from VAC and seeing the positive outcomes of their child was a positive part of their lives. Father (6) wrote: *'I am so happy that we have association for autism and Vientiane Autism Centre. I might not be able to express clearly my experience but together we can help the ASD child to learn to live independently'*. Carer (15) expressed her gratitude: *'I feel bless to know and have the centre working with us'*. Mother (11) described the discontinuation of her child's behaviour of hitting himself, destroying objects and not listening, being a positive for her and her family's life. Mother (1) noticed the improvement of her child after attending VAC and expressed her hope for her child to continue making progress in many areas in the future.

Four families identified that having knowledge and strategies to handle the child's behaviours, to facilitate and deal with communication difficulties and activities of daily living were a positive part of their journey as parents. Mother (19) explained: *'The positive part is that my son and I are always together side by side …. From this closeness year by year help me understand him better of what he wants and why he feel angry. From these observation, the problem relates to his anger is gone'*. Carer (5) described her understanding of the function of behaviours from observation: 'I *look after the child very closely and have learnt different meaning and communication clues from his behaviour'.* Mother (17) reflected on the positives of learning coping strategies for dealing with her child's difficulty in self-regulating emotions: *'When my child is upsetting and showing behaviour of concern, I will hug him, kiss him and speak to him gently'*. And also in engaging him in daily life activities; *'He is able to make fried egg now'*; toilet training; going shopping; and other activities of daily living and life skills. She also identified that raising a child with ASD required time devotion, close attention and understanding of the child's feelings.

A few parents tried very hard to stay positive while experiencing the constant and highly demanding need to provide vigilant care, supervision and support in raising a child with ASD.

Most parents reported the need for external support from the general public and broader community in order to provide improved access to education for many more families yet to be identified who may still be feeling ashamed to open up about their child's condition. Father (22) wrote: *'I believe that there are many families who have autistic children that do not have an opportunity to access to proper educational services. More awareness raising is needed for people in the society*'. Sibling (3) commented on the parents' shame caused by discrimination: *'I want to see the society give the right to a child with ASD to be part of the society … accept … so that their parents do not feel shame to take their child out of the house'*.

It is clearly reported by mothers and fathers that positive adaptation derives from supportive relationships within and outside the family. While this group of parents who participated in this current study reported great resilience, they also reported the struggles and challenges of finding a life balance in living in the community with the limited formal support network.

CHAPTER FIVE

5. DISCUSSION

5.1. Introduction

This chapter will discuss the findings in light of the researcher's interpretation of the data and the current literature. Hermeneutic phenomenology allows an opportunity for the researcher's own lived experience to merge with that of the participants to provide a distinctive perspective on parenting a child with ASD in the lower-middle income economy of Laos. The researcher's unique parenting experience in both developing and developed countries is an important contribution in the absence of a sustained discourse around the provision of disability support in Lao PDR which can further support the findings of this research.

The present study has revealed how having a child with ASD affects Lao family life. It has found that Lao families who have a child with ASD who participated in the study have shared common experiences with other parents in both Western and non-Western countries. Yet, there have been experiences that are unique to the Lao context, specifically due to the impact of living in a developing country where knowledge about disability and government and professional supports are limited. Central to the discussion is the importance of the family in Laos who have a great deal of skills, resilience and capabilities. Any professional working in the Laos context must not undermine what is already there, they must underpin it.

Laos is in the unique position to learn from the disability sector of developed countries in order to avoid the path of over-professionalising the available supports. It is important to that therapy and education supports continue to empower and support the family unit. This chapter presents a discussion which links the findings from existing literature regarding parenting a child with ASD and the application of theory to further explain these findings.

5.2. Universal experiences of parenting a child with ASD

The complexity of parenting a child with ASD and its pervasive impact on parents' emotions, family finances, family functioning, and social participation is well recorded in the literature (Corcoran et al., 2015; Gau et al., 2012; Ha et al., 2014; Lendenmann, 2010; Martinez, 2009; Myers, Mackintosh, & Goin-Kochel, 2009; Ogston et al., 2011; Woodgate et al., 2008; Wang et al., 2013). It is clear that the Lao participants share many of the universal experiences when raising a child with ASD.

5.2.1. Mixed feelings and emotions

When asking participants in the study to describe their feelings and emotions associated with raising a child with ASD, most spoke of the mix of both negative and positive feelings and emotions such as feeling sad, disappointed, embarrassed, in denial, worried about the child's future, tiredness due to the support needs and hopelessness while also feeling happy, proud of their child and encouraged when they saw their child make progress. This explanation is consistent with reports of parenting a child with ASD in other countries (Corcoran et al., 2015; DePape & Lindsay, 2015; Hoogsteen & Woodgate, 2013; Kuhaneck et al., 2010; Lendenmann, 2010; Phelps et al., 2009; Robert et al., 2014). The study by Corcoran et al. (2015) acknowledges that having mixed feelings when parenting a child with ASD is normal. It is important that practitioners explain to families that experiencing difficult emotions is common. Families should be able to express freely their feelings and own experiences without fear of judgement.

5.2.2. Financial impact

Lao families in this current study repeatedly reported that having a child with ASD has an impact on their financial situation. Families reported there is a high cost involved in education, special resources and the diagnostic process for their child with ASD. This is by no means a unique situation. Families in Western countries reported having a child with ASD is financially burdensome, despite having access to government support services (Hunt-Jackson, 2007; Ogston et al., 2011; Wang et al., 2013). Martinez (2009) identified that the lack of financial support is a key barrier for many families. Eskow et al. (2011; cited in Gardiner & Iarocci, 2012) indicated families with a child with ASD who received state funding in the USA reported higher levels of life satisfaction compared to those who received no financial support. This experience was supported by families in Laos, who received financial assistance from the AfA, reported it was helpful, especially for the continuation of their child’s education. It is clear financial support plays an important role in addressing the needs of the families who have a child with ASD. While money is important, it is also important to recognise that money is only one domain of family functioning. Maintaining the family’s wellbeing requires a holistic approach.

5.2.3. Impact on family functioning

Lao families in the study reported having similar experiences regarding family functioning as other Western families who have a child with ASD. Raising a child with ASD impacts upon marital satisfaction, family dynamics, sibling relationships and the constant need for adjustments in day-to-day life (DePape and Lindsay, 2015; Freeman et al., 2012, Gardiner & Iarocci, 2012; Gau et al., 2012; Kent, 2011; Myers et al., 2009). It is challenging to maintain positive family relationships due to the time demands and need for vigilant care of the child with ASD. The stress from the demanding caring role, mixed emotions and tiredness have a heavy impact on family cohesion. This impact is often reported as lack of time spent as a couple, unequal contact time between siblings and the general lack of balance in the family life (DePape & Lindsay, 2015; Gardiner & Iarocci, 2012; Gau et al., 2012; Kent, 2011; Myers et al., 2009; Ogston et al., 2011). This finding indicates that there is a need to consider the interconnected nature of families in the planning of support for the child with ASD. It is important that the child with ASD is not treatedas a separate entity from their family, but to recognise the role the family plays in the support of the child and ensure their needs are met.

5.2.4. Negative impact on social participation

Impact on social participation is similar between Lao families who have a child with ASD in this current study and other Western and non-Western families, especially on the restriction of ASD friendly activities outside of the home environment, loss of friends, discrimination (Myers et al., 2009; Woodgate et al., 2008) and cultural beliefs regarding disability (Ha et al., 2014; Wang et al., 2013). The negative themes identified by the parents of a child with ASD in the study by Myers et al. (2009) were social isolation as parents experienced difficulties going outside the home with their child with ASD as well as receiving poor treatment by members of the community. Similarly, participants in this current study reported having a hard time participating in activities outside of the home due to the constant care required and the lack of understanding and acceptance in society. This resulted in the parents being judged on their parenting style and their child being discriminated against due to demonstrating behaviours of concern whilst out in the community. The social and cultural view of a child with disability bringing shame and being regarded as parenting failure were found in the studies conducted with other Asian families who have a child with ASD (Ha et al., 2014; Wang et al., 2013). Parents often reported feeling shame and embarrassment and as a result, they were reluctant to seek help from outside supports and resources (Ha et al., 2014; Wang et al., 2013). Lao parents having a child with ASD who participated in this current study reported these same feelings of shame and embarrassment. This finding stresses the need for public education about ASD in the wider community and the need for strong support networks for families in order to feel acceptance and belonging such as through parent advocacy groups.

5.3. Experiences of parenting a child with ASD unique to the Lao context

As mentioned in Chapter Two, people with disabilities in Laos face challenges in all areas including cultural, social, economic, political and community support services. Accessing the necessary services such as education, health care, vocational training and employment is very difficult particularly for those with intellectual disability. Public buildings, schools and hospitals are rarely accessible. People with disabilities are very poor because there is no national fund for the development of people with disabilities. The capacity for people with disabilities to influence policy change is still limited (Handicap International, 2016). Discrimination against people with disability remains common in the society (Association for Autism, 2016; Handicap International, 2016).

Lao public capital expenditure including education investment and spending is highly dependent on official developmental assistance (ODA) (Asian Development Bank, 2011; DFAT, 2014). Funding mechanisms from the government to local organisations do not exist (Handicap International, 2016). Civil organisations access some funding sources by small grants from donors through the European Commission, United Nations Agencies, the World Bank and some bilateral donor agreements (Asian Development Bank, 2011). The

Lao civil society organisation (CSO) decree was issued in 2009 allowing the formation of local not-for-profit organisations (Asian Development Bank, 2011). The new development of a civil society movement combined with the lack of structured funding mechanisms will continue to be a key issue for disability organisations in Laos including Association for Autism.

5.3.1. The impact of being in a low-middle income developing country

Lao families who have a child with ASD in the study expressed the similar desire to see positive outcomes for their child as other families in Western countries do. However, the ability to access supports such as schooling, professionals, childcare, and participation in the community is highly limited according to the findings from this thesis. Similar limitations have been identified in the Ha et al. (2014) and Tran et al. (2015) studies conducted in Vietnam, particularly in the area of assessment and diagnosis of ASD, limited access to services and well-trained professionals for the child with ASD as well as limited political and economic supports.

Seventy per cent of the participants in this current study came from a low-income household where the average earning was less than US$ 550 per month while school for the child with ASD (at VAC) costs about US$ 242 per month, representing a significant portion of the family's total income. For many participants in this current study providing basic education for the child meant giving up on other family member's basic needs such as limiting spending on food, clothing, utilities and activities. With the lack of public knowledge about ASD, limited human resources capable of dealing with ASD at school level and a lack of therapy options, participants felt they had little choice but to access the high cost basic education and therapies provided by VAC for their child. This disparity between cost of services (such as education and therapy) and family income appears to be a large point of difference between parents of children with ASD in the developed countries compared to the participating families in Laos. In developed countries parents were more worried about paying extra for therapeutic supports for their child (Myers et al., 2009; Ogston et al., 2011) as the basic education was covered by government funding. It is clear that the degree of difficulties is greater in the Lao context where poverty and disability coexist.

5.3.2. Lack of support from the government

The lack of financial and policy support and action from the Lao Government were regularly expressed by the participants as barriers which exacerbate families' difficulties. There are currently no diagnostic services available in the country and if families want to access these it incurs additional spending due to the need to travel to Thailand. There is a compounding effect for families who earn little income but are required to spend money on the necessary step of assessment and diagnosis. The lack of diagnostic services and no national definition of ASD in the Lao language also impacts the ability to educate the community and train relevant professionals such as special education teachers and social workers.

The number of children diagnosed with ASD is increasing every year throughout the world (Samadi & McConkey, 2011) yet the Lao society and its government seem to fail to recognise the impact and the implications of the diagnosis of ASD on the child's development and on family life. This similarity was found in the study of Samadi and McConkey (2011) who discuss 'Autism in Developing Countries: Lessons from Iran' and the study of Wang et al. (2013) who focussed on 'Parenting stress in Chinese mothers of children with Autism Spectrum Disorders'. The findings indicated it is impossible to identify the breadth of the issue (prevalence rate of ASD) or provide education for the community without ASD diagnostic services and the language of ASD existing in the country.

5.4. The importance of education

The lack of access to basic education and therapies for the child with ASD was repeatedly reported by the participants in this current study. This limitation reflects that greater effort is needed to ensure individuals with ASD have access to education as part of their basic human rights, as currently, these students are missing out.

It is clear parental education is also highly important, not only to support and provide positive outcomes for their children, but education can provide parents with the platform to further develop their coping skills (Kuhaneck et al., 2010). The findings indicated that participants in this current study experienced multiple hardships due to living in a low-middle income developing country as well as coming from a low income status. These families are the main support system to their child with ASD. Parents and families members often have to provide educational services to the child in addition to parenting and therapy roles due to the very limited professional services and supports.

Discrimination toward people with disability is common in Lao society. Participants of this current study repeatedly expressed that they felt hurt, embarrassed, and shamed every time they were judged on their parenting style and, as a result, they often became isolated from the mainstream society. Similarly, the experience of discrimination and stigmatisation were found in the studies conducted in both Western and non-Western countries (Corcoran et al., 2015; Ha et al., 2014; Hunt-Jackson, 2007; Lutz et al., 2012; Tran et al., 2015; Wang et al., 2013). These studies identified the necessity for public education to overcome this social barrier. It is clear that the child with ASD, their families and the community are interconnected and education of a diverse range of people and the provision of supports is important in order to facilitate positive outcomes for everyone.

5.4.1. Education for the child with ASD

As previously discussed, living in a low-middle income developing country poses additional challenges for Lao families raising a child with ASD, particularly regarding access to basic education. Participants in this current study reported their child had been refused access to public school due to the school's inability to handle the child's behaviour and a lack of teacher knowledge and resources about ASD. Some parents wanted their child to access mainstream schooling but had to pay extra fees in order for the school to accept their child, with no guarantee of quality outcomes. Although the Government of Laos promotes non-discrimination, equal rights in education and employment for all its citizens, the implementation of these policies at the practical level remains problematic. This topic was also discussed in the *'Australia-Laos Education Delivery Strategy 2013-18'* by the

Australian Government Department of Foreign Affairs and Trade (DFAT) in 2014, which reported the major issues in the Lao education system were low participation and high dropout rate, limited accessibility; and a low quality of education. This further limits the educational opportunity for children with ASD and the perceived difficulties of including them in mainstream schools.

Education was highly valued by the Lao participants of this current study, despite many having a low-income status. This was reflected in the way participants continued to send their child to VAC despite costing many families more than half of the family income and for some, around 80 per cent of the family earnings per month. Having the right education and support benefits both the family and the child with ASD as half of the participants identified access to education, continuation of education and working collaboratively with VAC as one of their main strategies to help them cope. Access to education and the opportunity for inclusion were also among the top three factors that Lao families in the study identified helped to enhance their lives and bring about the best possible outcomes for their child.

It is clear that improving the quality of basic education is highly important in the Lao context. The high dropout rate among general students may reflect the need to adjust the teaching practices for diverse student types, this includes those with ASD. In the study by Reupert, Deppeler and Sharma (2015), Australian parents of a child with ASD identified that good teaching practices for students with ASD were good teaching practices for all students because they required schools and teachers to consider students' diverse needs individually and apply a flexible approach to their teaching. These mothers suggested various strategies such as, having a safe space, structured school and free time, flexible timetables, curriculum and staffing, as well as the need for greater collaboration between parents, teachers and community agencies. The approach for inclusive education in Australia could be adopted to inform the future direction of teaching practice in Laos.

5.4.2. Education for the parents

The support options available to Lao parents who have a child with ASD were extremely limited. When participants were asked to describe the strategies and supports they used in order to help them cope; immediate family members helping each other, as well as working collaboratively with VAC were regularly mentioned. The study of Gupta and Singhal (2005) indicated there was a large body of literature supporting the involvement of parents as therapists in their children's intervention programs and this involvement both helped to increase the intensity and individualisation of the intervention for the child, as well as being a cost-effective model of service delivery. The effects of including parents as direct service providers increase the availability of intervention, which positively impacts the child with ASD and their wider family (Gupta & Singhal, 2005). Therefore, the education of parents should be highly valued, not only to provide positive outcomes for the child but also as a problem-solving and coping technique to help decrease isolation and stress for parents and the family as a whole.

Participants in this current study indicated a strong value placed on education not only for their child but also for themselves. This was clearly described as a strong coping mechanism, where 30 per cent of the participants invested in the task of seeking knowledge about ASD and therapy options from other parents and professionals in Thailand. Mothers of a child with ASD in the United States supported this experience, believing that 'knowledge is power' to help them advocate for their child's needs (Kuhaneck et al., 2010). Lao families with a child with ASD in this current study reported that working collaboratively with VAC and the teachers as well as other parents was very useful in order to learn practical techniques to work with their child on various issues such ass daily living skills, communication and getting a haircut. It was identified that support groups and parent-to-parent networks are a useful platform for information exchange, group therapy and non-judgemental open interactions (Lutz, Patterson & Klein, 2012; Phelps et al., 2009). It is also helpful for families to achieve time for themselves, 'me time' especially for mothers (Kuhaneck et al., 2010). This reflects that having the right support, knowledge and positive wellbeing empowers families to continue improving outcomes for their children with ASD and the family as a whole.

The nature of parenting a child with ASD means that often parents are required to put their child’s needs ahead of their own due to the constant demand for care including feeding, dressing and bathing (Hoogsteen & Woodgate, 2013). This finding was consistent with the experience of participants in this current study, where it was identified that the high demand for care was one of the main elements that impacted family functioning, employment, friendships, and community involvement. Therefore, parent education programs must aim at working with parents and family members, providing them with practical strategies to help them juggle their multiple roles.

Kuhaneck et al. (2010) suggest helping parents to create routines that work effectively for the family, such as morning and bedtime routines, and the use of visual schedules to help the child learn these routines. Kuhaneck et al. (2010) also recommended creating a local group of well-trained respite providers in the community to fill the gap where respite care is limited. Education of family members in Laos could incorporate knowledge about family teamwork (Kuhaneck et al., 2010) and ways in which to support family cohesion (Wang et al., 2013).

5.4.3. Education for the community

A lack of education and knowledge about ASD in Lao society combined with negative attitudes towards disability has been identified as one of the main barriers for both the child with ASD. Previous research found parents hold a common hope for their children’s good health, wellbeing and future accomplishments (Howell & Larsen, 2015). Participants in this current study also hoped their sons and daughters would be able to live a ‘typical’ life like other children without disability. They wanted their children to experience the ‘good things in life’ (Osburn, 2006) that other Lao citizens have access to, such as education, healthcare, employment opportunities, recreation and access to public facilities. The lack of community understanding about ASD is a strong barrier for Lao parents to maintain employment, friendships and be part of the community. Schultz and Held (2014) defined having a positive life outcome means to be accepted in the community, to experience a sense of belonging and to be able to contribute according to your strengths, yet these are experiences that families who have a child with ASD in Laos struggle to maintain.

The necessity for public education has been identified in many studies carried out in other developing countries such as India (Gupta & Singhal, 2005), Vietnam (Ha et al., 2014), China (Wang et al., 2013) and in Iran (Samadi & McConkey, 2011), but the benefits and the impacts have not been discussed in detail. However, by considering the disability movement in the West that led to the development of the United Nations Convention on the Right of People with Disability (UNCRPD) (2006), it can be argued the core benefit of public education on disability rights is to shape society's attitudes toward respecting dignity, autonomy, rights and equal opportunities for people with disability in society (Shogren & Turnbull, 2014). The UNCRPD is an instrument and obligation for its signatory governments to incorporate the core concepts and approaches into their own policy agenda (Shogren & Turnbull, 2014). Laos became a signatory to the UNCRPD in 2009. It is important the Lao government incorporates education about disability and ASD for the community into its policy agenda as part of the obligation to the UNCRPD.

5.5. The importance of the family

The key finding of this thesis is that the family support network is central to the wellbeing of participants who have a child with ASD in Laos. Families stressed the need for cohesion, knowledge and skills to deal with their child's behaviour and communication issues. Studies conducted with parents of children with ASD in developing countries such as Iran, India, Vietnam and China confirmed the need to empower families in the absence of professional resources (Gupta & Singhal, 2005; Ha et al., 2014; Samadi & McConkey, 2011; Wang et al., 2013). The person-centred approach and family-centred approach are recommended positive practice in many developed countries. For example, the Australian Government's National Disability Insurance Scheme aims to put families in control so the individual with disability is empowered to make choices about what services are most important for them (Walsh & Johnson, 2013). Therefore, it is important to consider family interventions that will enhance family coping, enabling them to flourish with warmth, support and cohesion.

5.5.1. Family Resilience

When asked to give an overall reflection of the journey of raising a child with ASD in Laos, some participants responded positively, describing their family journey from diagnosis; learning to accept and move forward, they demonstrated a strong sense of resilience. These participants identified factors contributing to their family's resilience as having a positive mindset, as well as knowledge and strategies to cope with challenges. These findings were consistent with the study of Black and Lobo (2008) which reported that families generally have the qualities to develop resilience particularly at times of crisis. The concept of resilience discussed in Black and Lobo (2008) identified that the two core ingredients for resilience are family interactions and optimistic attitudes, where families continue to love and support one another in both good and bad times. Much of the literature on the lived experience of parenting a child with ASD in both Western and non-Western countries also revealed that parents learned to cope, survive and grow meaningfully out of their stresses and challenges in life (Anh, 2015; Corcoran et al., 2015; DePape & Lindsay, 2015; Freeman et al., 2012; Gardiner & Iarocci, 2012; Hoogsteen & Woodgate, 2013; Hunt-Jackson, 2007; Kuhaneck et al., 2010; Lendenmann, 2010; Martinez, 2009; Myers et al., 2009; Ogston et al., 2011; Phelps et al., 2009; Santoso et al., 2015; Schwartz, 2001; Smith et al., 2010). Some of the protective factors identified in these studies included having hope, having access to extended family and social support, financial support, and quality of community support services, many of which were also raised by the families in the Laos context.

Using a holistic approach to parenting a child with ASD assists parents coping with their difficulties. Kuhaneck et al. (2010) found that parents who cope and adapt better do this by acquiring more knowledge and skills in raising a child with autism, and simultaneously, look after their mental, physical and psychological wellbeing. Some parents become involved in volunteer work providing emotional support to others (Smith et al., 2010), advocating for access and services (Ha et al., 2014; Lendenmann, 2010; Phelps et al., 2009) and by simply being proactive. The protective factors discussed in these studies can be applied in the Lao context in order to maintain and strengthen resilience of the Lao family raising a child with ASD.

5.5.2. Family cohesion and functioning

Lao families who have a child with ASD reported the stress associated with the high demand for care affects the family's harmony. Some families identified that having a shared vision, role clarity and empathy to the needs of the child with ASD helps them to cope better. These participants stressed the importance of immediate family members supporting each other in both caring and educating roles for the child with ASD, focusing on daily living skills, social skills and community participation. This is consistent with the explanation of Olson (2000) cited in Black and Lobo (2008) that the family system that works well consists of three main elements which include 1) members feeling good about the family; 2) all members needs are being met; and 3) the development of relationships flows smoothly. Family cohesion enhances family confidence in dealing with issues (Black & Lobo, 2008). It is important for Lao families raising a child with ASD to understand the interactions and interconnection between family resilience, cohesion and functioning and receive support they need to maintain their family's functioning that will lead to family wellbeing and positive child outcomes.

The concept of family cohesion and functioning were discussed in Armstrong, Birnie-Lefcovitch and Ungar (2005) under the umbrella term of family wellbeing. In this current study , family wellbeing can be achieved through a number of aspects that involve 1) family's organisational structure; 2) interpersonal relationships; 3) parent psychological status and 4) parent self-efficacy (Armstrong et al., 2005). The family's cohesion, harmony, agreement on child rearing style, communication and conflict were classified under the family organisational structure. The interpersonal relationships include relationships between immediate family members and extended family members and friends. Parent self-efficacy refers to parents confident in dealing with their child's problems (Armstrong et al., 2005).

The findings of this thesis are consistent with the family wellbeing model by Armstrong et al. (2005) where some participants identified the source of their positive experiences of raising a child with ASD in Laos came from their family having shared empathy for the child and the value they placed on inclusive opportunities. Participants also identified that having understanding from family, friends and the workplace, as well as having the courage to explain about ASD in the community were part of their positive experiences. This reflects the need for family support and intervention that aims at improving family wellbeing, education, empowerment and advocacy skills. The parental emotional wellbeing and quality of their parenting leads to better family functioning and resilience in the child (Armstrong et al., 2005).

It is important to note that some Lao families who have a child with ASD in this study reported that the stress associated with the high demand for care affected their marital satisfaction and caused conflict between a husband and wife. Participants also reported having arguments due to family members' limited strategies to deal with the child's behavioural issues. Similar issues have been discussed by Black and Lobo (2008) where the essence of 'harmonious communication' can enhance clarity, open emotional expression, and collaborative problem solving within the family. Here, in the resilient family, problems and difficult emotions are recognised and communicated openly with respect, understanding and in a non-judgemental manner. The Black and Lobo (2008) study also identified about one-third of low-income families in the USA demonstrated weak communication skills as they tended to avoid or found it difficult to talk about their problems, similar challenges were expressed by parents (particularly fathers) in Laos (Orthner et al., 2004 cited in Black & Lobo., 2008). Knowledge about effective communication skills were beneficial when included as part of family support interventions for Lao families who have a child with ASD.

5.5.3. Approaches to working with Lao families who have a child with ASD

The discussion of the universal experiences and the unique nature of parenting a child with ASD in Laos, and the acknowledgement of the role that the family support network plays in maintaining the wellbeing of individuals, a framework that aims at empowering families will be discussed. Some effective approaches used in other settings may be considered appropriate to apply in the Lao context with the ultimate goal of improving family wellbeing to enhance positive outcomes for the child with ASD.

The strengths-based approach

The strengths-based approach recognises parental strengths and places the parent in the position of the expert on their child's status and needs (Carlson, Armitstead, Rodger, & Liddle, 2010). It emphasises an equal partnership between parents and professionals/service providers (Carlson et al., 2010) with an aim to empower families to consider their challenges not as damaging but rather as opportunities for healing and growth (Black & Lobo, 2008; Carlson et al., 2010). The key characteristics of a strengths-based approach include treating people with respect; enabling teamwork and collaboration; sharing of information, knowledge and skills; valuing social justice of acceptance, equality, participation and self-determination and promoting transparency with open communication (Carlson et al., 2010).

The natural learning environment approach

The natural learning environment approach has been discussed extensively in the education literature (Carlson et al., 2010). This approach considers assessing needs and incorporating learning and teaching in the variety of settings where children and families live, learn and play (Carlson et al., 2010). The aim of this approach is to identify and expand learning opportunities in everyday routines for children allowing greater opportunities to practice the skills and behaviours they need at home, in the community and school (Carlson et al., 2010). Therapists coach families and care providers during real life activities (Carlson et al., 2010). This approach is highly relevant in the context of intervention programs for families of lower socioeconomic status where families struggle with basic survival needs. Here, they should not be required to make greater adjustment toward learning new skills in other settings apart from their normal daily routines (Harry, 2002).

The family-centred approach

The family-centred approach values the choices made by families and attempts to ensure services meet the needs of all individuals in the family unit (Rosenbaum et al., 1998 cited in Carlson et al., 2010). The main characteristics of this approach include respecting and involving families in the decision-making process; acknowledging parents have the responsibility for their child's care; respect for each family member as an individual; whilst considering the needs and encouraging involvement of all family members (Carlson et al., 2010). Harry (2002) provided recommendations for services that aim at using family-centred approaches in culturally diverse groups of people to consider three main areas that include 1) collecting information about families in the naturalistic manner; 2) working on the family's zone of proximal development; and 3) the need to be flexible and responsive to the unique cultural needs.

The community-based family support therapy

Community-based family support therapy combines family-centred and strengths-based approach to apply in the natural learning environment (Carlson et al., 2010). Carlson et al. (2010) found families reported having positive experiences when adopting a strengths-based approach that utilised the natural learning environment in the provision of family-centred services (Carlson et al., 2010). Participants in a Carlson et al. (2010) study identified three main factors contributing to a positive experience, they were: working together; being positive; and information exchange. Seeing positive child outcomes is identified as one of the main elements contributing to parents' satisfaction and view of effective therapy (Edwards, Brebner, McCormack & MacDougall, 2016). This was also discussed as the ultimate goal of participants in this current study . They expressed clearly their positive feelings came from seeing the child progress which, in turn, gives them hope, faith and motivation to continue working hard. Participants in this study would be thought to benefit highly from professionals who adopt these community-based family support methods so that the current strengths that have been demonstrated to exist in families involved in this research are not lost but strengthened.

5.6. Chapter summary

This chapter presented a discussion based on the findings from the qualitative survey of Lao families who have a child with ASD. Findings were presented with links to literature on parenting a child with ASD, education and family theory. It is important to acknowledge the interconnected nature of education, family wellbeing and the child's outcomes as was reflected in the discussion. Particular attention was paid to the focus on strengths, coping and growth rather than on the difficulties associated with parenting a child with ASD in a developing country like Laos.

CHAPTER SIX

6. SUMMARY AND RECOMMENDATIONS

6.1. Introduction

This current study aimed to reveal the experience of Lao families who have a child with ASD. It explored the common experiences amongst families who have a child with ASD around the world in order to determine whether the experience of families in Laos were similar or different. This provided a greater understanding of how ASD affects families in the different cultural context of life in Laos. The study aims to provide recommendations based on the findings that Lao families who have a child with ASD face multiple levels of complexity associated with the ASD diagnosis, combined with the nature of being from a low-middle income developing country. However, the coping systems and life journey of the participants revealed a great deal of their inner quality and family resilience.

This chapter provides an overview of the findings, makes recommendations for future research, describes implications for practice and outlines concluding statements regarding the outcomes of this current study.

6.2. Overview of the findings

The significant themes that were derived from this current study are:

1) The impact of ASD

   Lao families who participated in this study of families living with a child with ASD reported experiencing challenges across a range of major life domains such as; emotional wellbeing; financial circumstances; family relationships; employment; friendships and community involvement.

2) Family coping and adaptation

   This theme revealed parents self-reported supports and strategies which helped them cope including strategies that benefited both the family and the child. Maintaining family cohesion, extended family support, child care support, having knowledge and skills about ASD, the child having access to quality education and seeing the child have positive outcomes were among the main coping strategies.

3) Family support needs

   This theme showed a combination of supports that families identified would enhance their life living with a child with ASD. The subthemes were ranked and prioritised as per parents' accounts. The subthemes regarding desired family support needs were namely; having access to professional services; access to and continuation of their child's education; having opportunity for inclusion; having more opportunity for information sharing with other parents who have a child with autism; and the call for more policy support and action from the government.

The knowledge constructed from the interpretation of participants experience has produced an insightful and distinctive perspective on parenting a child with ASD in Laos. Multiple areas discussed by the participants were also a reflection of my own lived experience as a parent who has a child with ASD, which was the driving force for choosing to undertake this current study . Using participants' accounts, the researcher's understanding of their lived experience revealed the following:

1) There are universal experiences linked to parenting a child with ASD, such as:
   - Mixed feelings and emotions
   - Financial impact
   - Impact on family functioning
   - Negative impact on social participation.
2) There are experiences of parenting a child with ASD that are unique to the Lao context, these are:
   - The impact of living in an low-middle income developing country
   - Lack of support from the government.
3) There is a strong need for education in multiple areas:
   - Education for the child with ASD
   - Education for the parents
   - Education for the community.
4) The importance of the family is significant to the Lao context and consideration of the following points is important:

- Family resilience
- Family cohesion and functioning
- Approaches to working with families.

Based on this new knowledge and greater understanding of the experience of having a child with ASD in Laos, the next section will recommend a framework and approach for policies and professional support services in the context of these themes. The implication for practice includes opportunities for further research.

6.3. Recommendations and implications for practice

6.3.1. Adopt and implement standardised ASD definition, assessment and diagnostic services

The lack of an ASD definition, assessment and diagnostic services available in Laos pose a major barrier to having reliable prevalence data and estimation of support costs and therefore access to relevant intervention requirements and practices. Professional development, ongoing education and ASD research cannot happen without a standardised definition of ASD and model of support. Lao Ministry of Public Health may consider adopting the use of Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) (2013) which provides the current internationally recognised definition of ASD. The DSM-5 provides standard language for clinicians, researchers, and public health officials and has been adopted by many countries in order to communicate universally about mental disorders. The manual also sets out diagnostic criteria and classification for ASD. The ASD definition, assessment and diagnostic criteria identified in the DSM-5 can be translated into Lao language and applied in hospital, clinic, university, college and school settings. This adoption can also be used as the country's proactive action as a signatory member of the UNCRPD (see figure 6.1).

6.3.2. Professional development

Participants reported the desire to seek support that will bring the best possible outcomes for their child with ASD; having access to professional support services was high on their priority list. Professionals who work with Lao families and their children with ASD need to provide services that underpin not undermine the family. Different approaches to family empowerment have also been discussed. As one of the fastest growing economies in South East Asia and the Pacific Region and with Laos being upgraded into a lower-middle income economy bracket improvements in the health and education sectors are expected. Moving forward, Laos needs to invest in short, medium and long-term disability related professional development. This development will not only benefit individuals with ASD and their families but also individuals with other forms of disability, the wider Lao society and the sustainability of the country's development effort.

Short-term approach

In the short-term, provision of regional or international allied health professionals available at major hospitals in Vientiane should be considered. This could include speech therapists, occupational therapists and psychologists. These professionals could provide assessment and diagnosis, early intervention and support services to families, as well as a knowledge transfer approach with Lao public health officials, teachers and parents (see figure 6.1).

The provision of short courses of six months to one year in Special Education, Developmental Education, and Social Work should be included in the curriculum at teacher colleges as a strategy to meet the demand for the disability related workforce. Regional and international experts could be invited to provide this relevant education with interpreter support as a way to build the capacity of Lao education officials (see Figure 6.1).

Medium and long-term approach

For the medium and long-term approaches, the Lao younger generation including individuals with disability, siblings and families, as well as government officials, should be encouraged and supported to study overseas in the area of special education, disability and developmental education, speech therapy, occupational therapy, psychiatry, psychology, behaviour intervention and physiotherapy (see figure 6.1) in order to bring these skills back to Lao in an effort to broaden the availability of these professions in the country. In order to gain sustainability, it is recommended local universities in Laos work with international universities in order to develop a curriculum so local people can become future allied health professionals. Disability inclusion rights should be integrated in to all university courses (e.g. Teaching, business, design, health professionals etc.) so that inclusion becomes the responsibility of all members of society.

6.3.3. Ongoing education

Education is required at all levels including education for the child with ASD, their parents and families and the wider community. Improving access to basic mainstream education for children with ASD is an urgent need. This means inclusive primary and secondary schools need enough resources to implement their work in order to support a more diverse student cohort, especially in the area of human resources. The teacher:student ratio policies for schools will need to be adjusted to allow more teachers in the inclusive schools to support the child with ASD. VAC has been working on a co-teaching practice approach with primary and secondary schools in Vientiane where children with ASD from VAC are placed in the mainstream setting. An evaluation of this co-teaching practice could provide better understanding of the outcomes and the needs to further improve and apply this strategy at other schools if it is deemed effective. Evidence-based teaching practices using child-centred and strengths-based approaches should be encouraged and taught explicitly to teachers, and policy should be reflective of inclusive practices (see Figure 6.1).

Provision of education and training to support family resilience, cohesion and functioning, as well as effective communication skills for parents and other family members would be beneficial. Ideally this should be embedded in the way professionals work with families. Having social workers who are capable of providing counselling services to family members would also be beneficial. AfA has established a parent consultation unit using the peer-to-peer approach where mothers are trained to help other mothers. Having professionals to facilitate and work alongside family members can enhance their skills in providing counselling and emotional support to one another (see figure 6.1).

Training on UNCRPD principles, disability rights, concept of accessibility, universal design and inclusion are all necessary for the Lao community, including government offices. There needs to be a shift in thinking regarding the perception of disability away from the use of a medical model which discriminates towards the social model of disability. Ways to reach out to the community may be by creating short videos demonstrating what it is like to live with a disability, highlighting the strengths and the abilities of the individual, which could be played in a public forum. Success stories of people with disability including ASD should be published regularly in the national media. Having a television program where people with disability are represented and stories of disability both in Laos and in other countries can be beneficial. Creating educational tools such as storybooks or textbooks based on positive disability role models which use pictures or symbols of disability could be very useful in creating a shift in perception in the general public. Policy based upon the UNCRPD principles should be adopted by the Laos government in order to support this level of inclusion in the wider community (see Figure 6.1).

Standardised ASD Definition, Assessment and Diagnostic Services

ASD Research

Further study on various issues relevant to the need, perception, motivation, practices in education, families, society and at a national policy level

Translation of existing research and resources from around the world into the Lao language

Cooperation with ASD research centres at both regional and international levels

The development of a knowledge database for students, parents, teachers and professionals

Professional Development

Allied Health professionals available in local hospitals for diagnosis and support.
Speech Therapists
Occupational Therapists
Psychologists

Short Term Professional Development.
Special Educators
Developmental Educators
Social Workers

Long Term Professional Development.
Special Educators
Developmental Educators
Social Workers
Speech Therapists
Occupational Therapists
Psychiatrists
Psychologists
Behaviour Specialists
Physiotherapists

Ongoing Education

For Child with ASD
Early intervention
Evidence-based teaching practice
Child-centred & Strength-based approaches

For Parents & Families
The concept of family resilience, cohesion and function
Effective communication skills

In the Community
UNCRPD Principles.
Success stories of people with disabilities.
Public awareness campaign about disability, accessibility and inclusion.

In the Education Sector
Knowledge about disability.
Adopting evidence-based teaching practices
Professional resources available to support teachers

Figure 6.1 Framework and recommendations for future policy and practice

6.3.4. ASD Research Centre

Having an ASD Research Centre would be beneficial in Laos especially when run in parallel with assessment and diagnostic support, professional development and education. There is a significant amount of research conducted in ASD related to therapy, practice and family support. International and regional research needs to be translated into Lao language to help inform and improve local knowledge and practices. Access to the existing knowledge from around the world is vital for future professional development. Students, parents, teachers and lecturers will then be able to learn from other countries and apply that knowledge to the local context.

AfA may also incorporate the recommendations from this research into their service delivery and evaluation for their members. Making knowledge available to share amongst Lao society would be highly valued. AfA may also cooperate with other ASD research centres at both regional and international level, government and donor countries to advocate for Research Centre to be set up at National University of Laos (see Figure 6.1).

6.4. Study challenges

Challenges and limitations of the present study include:

1) Since the researcher was the Co-founder and President of Association for Autism and a current Board Member, there was a perceived conflict of interest in this research project. The conflict of interest was managed through the distribution of the letter of introduction, information sheet and consent form through a non-AfA member. Using a research intermediary avoided the need for face-to-face interaction between the principal researcher and the participants to address the power role. However, the researcher’s name was included in the recruitment materials so participants may have felt some pressure to present positive reflections about their experience with AfA and VAC.

2) It should be noted that this research targeted people who are receiving services from and have links with the organisation AfA. The results therefore may not be

generalised to represent the whole population in Laos. The results can only be interpreted in context as the opinion of this specific group of parents who have a child with ASD and were receiving some services and support. While the research targeted members of AfA, this was also done for practicality; accessing multiple families who have a child with ASD would be almost impossible in Laos without doing this through the only ASD service currently available in the country.

6.5. Future research

The results of this current study, the high response rate of family members wishing to complete the qualitative survey to tell their story, as well as the current lack of research evidence regarding parenting a child with ASD in Laos is indicative of the need and urgency for further research in this area. The present study described the experience of parents who have a child with ASD with limited understanding of severity level of the condition; however, the researcher believes that it would be favourable for research to be undertaken on parents of a child with ASD who fall into similar range of severity level, particularly level one, level two and level three as specified in the DSM-5. Research completed with parents based on the severity level of the child's diagnosis may reflect specific needs for intervention within each group.

Having noted the challenges and limitations of the study design, it would be beneficial to expand on the findings of this research by including populations in other provinces for comparison. This will help determine whether the children and their family's support needs and coping resources are similar and sgain a bigger picture understanding about what life is like for a family who has a child with ASD in all provinces of Laos. Following this, expanding the research scope to cover mainstream school teachers' perspectives on disability in general and ASD, could enhance the understanding of the issues and inform the focus of the intervention, particularly within the dimension of education which was of significant concern of the families in this study.

Similarly, expanding the research scope to cover the health sector's understanding of disability and ASD could provide evidence for the urgency and training needed for having proper assessment and diagnostic procedures in place.

6.6. Conclusion

Lao families who have a child with ASD are in real need of support from a societal, a service, and a governmental perspective. The findings from this current study revealed this group of participants have made great personal and family sacrifices to maintain education for their children. The policy makers need to take concrete action towards assisting people with ASD and their families. Identifying as a developing country, with limited resources and funding should not be used as an excuse not to act; the recommendations provided within this thesis should be achievable despite the low income status of the country. Despite a lack of funding in government, the government is in a strong position to develop policy and accept the DSM-5, which will underpin and direct donors to support the development of a strong disability sector.

This study provided recommendations regarding supports for families, professionals and for disability advocacy based on evidence-based practices from around the world that can be implemented at a reasonable cost. Further delay in acting on this issue creates a higher risk of family dysfunction and further personal and societal challenges. The findings of this thesis can serve as evidence for government policy makers, funding providers and public health and education officers to incorporate family support needs into policy and support the need for collaboration with local and international researchers and donors.

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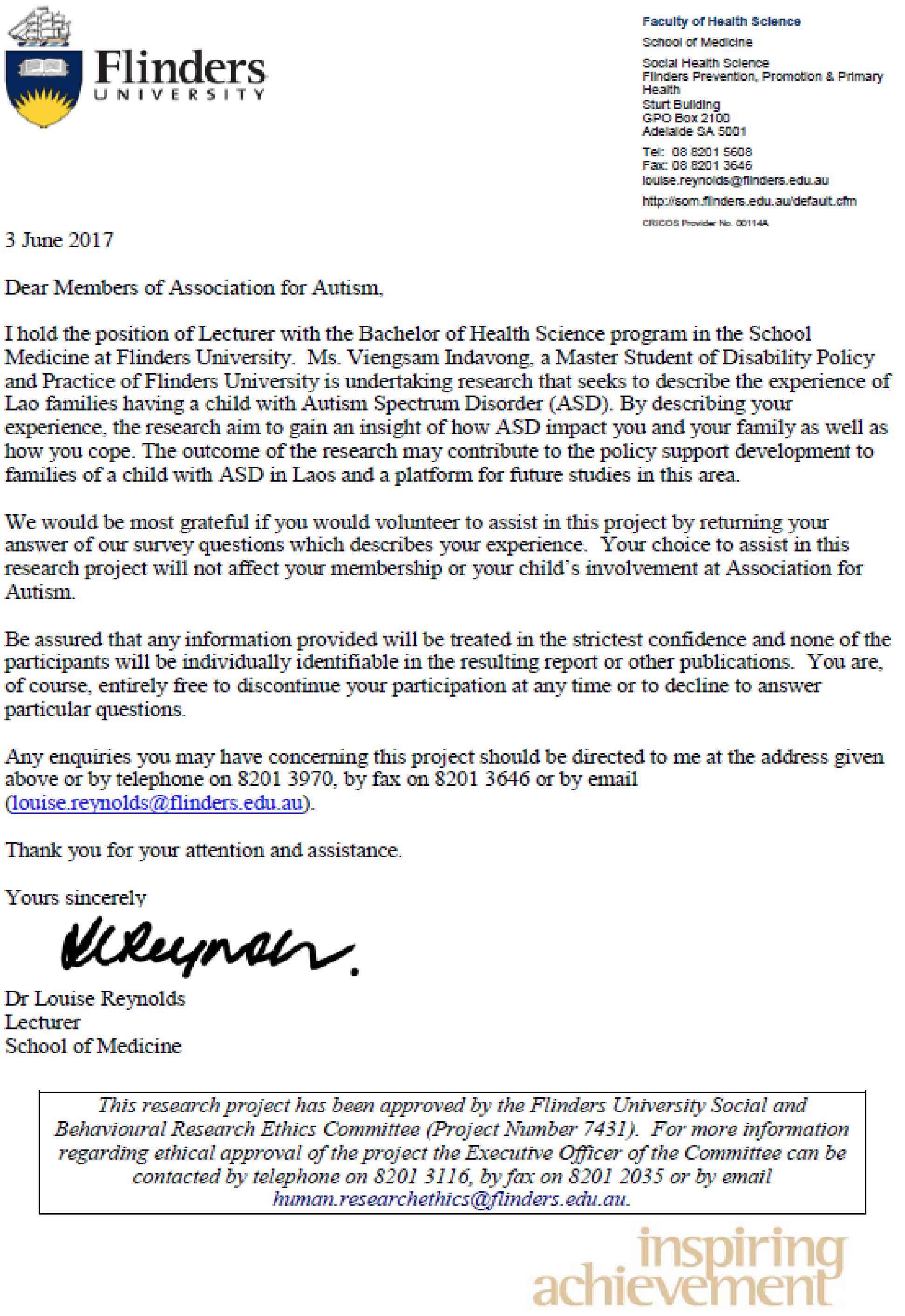
APPENDICES

Appendix 1: Letter of Introduction



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CRICOS Provider No. 00114A

3 June 2017

Dear Members of Association for Autism,

I hold the position of Lecturer with the Bachelor of Health Science program in the School Medicine at Flinders University. Ms. Viengsam Indavong, a Master Student of Disability Policy and Practice of Flinders University is undertaking research that seeks to describe the experience of Lao families having a child with Autism Spectrum Disorder (ASD). By describing your experience, the research aim to gain an insight of how ASD impact you and your family as well as how you cope. The outcome of the research may contribute to the policy support development to families of a child with ASD in Laos and a platform for future studies in this area.

We would be most grateful if you would volunteer to assist in this project by returning your answer of our survey questions which describes your experience. Your choice to assist in this research project will not affect your membership or your child's involvement at Association for Autism.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8201 3970, by fax on 8201 3646 or by email (louise.reynolds@flinders.edu.au).

Thank you for your attention and assistance.

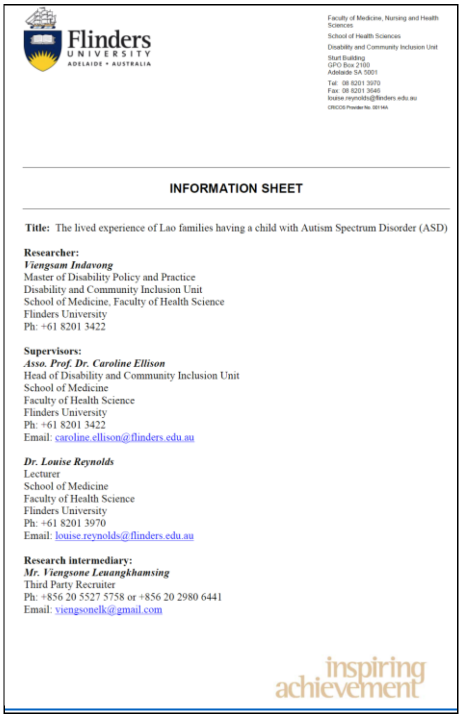
Yours sincerely

Dr Louise Reynolds
Lecturer
School of Medicine

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7431). 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.

inspiring achievement

Appendix 2: Information Sheet



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INFORMATION SHEET

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Third Party Recruiter
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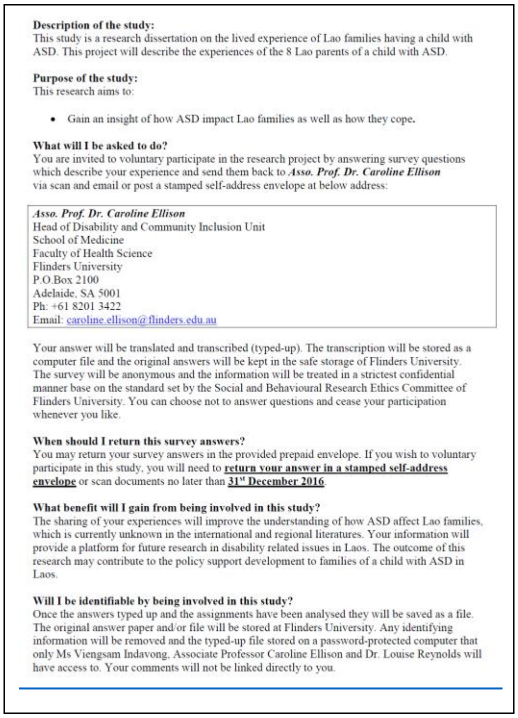
inspiring achievement



Description of the study:
This study is a research dissertation on the lived experience of Lao families having a child with ASD. This project will describe the experiences of the 8 Lao parents of a child with ASD.

Purpose of the study:
This research aims to:

- Gain an insight of how ASD impact Lao families as well as how they cope.

What will I be asked to do?
You are invited to voluntary participate in the research project by answering survey questions which describe your experience and send them back to ***Asso. Prof. Dr. Caroline Ellison*** via scan and email or post a stamped self-address envelope at below address:

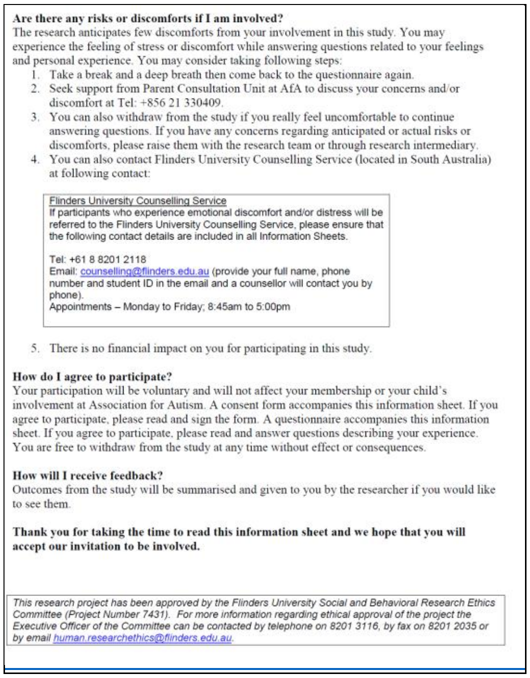
Asso. Prof. Dr. Caroline Ellison
Head of Disability and Community Inclusion Unit
School of Medicine
Faculty of Health Science
Flinders University
P.O.Box 2100
Adelaide, SA 5001
Ph: +61 8201 3422
Email: caroline.ellison@flinders.edu.au

Your answer will be translated and transcribed (typed-up). The transcription will be stored as a computer file and the original answers will be kept in the safe storage of Flinders University. The survey will be anonymous and the information will be treated in a strictest confidential manner base on the standard set by the Social and Behavioural Research Ethics Committee of Flinders University. You can choose not to answer questions and cease your participation whenever you like.

When should I return this survey answers?
You may return your survey answers in the provided prepaid envelope. If you wish to voluntary participate in this study, you will need to **return your answer in a stamped self-address envelope** or scan documents no later than **31st December 2016**.

What benefit will I gain from being involved in this study?
The sharing of your experiences will improve the understanding of how ASD affect Lao families, which is currently unknown in the international and regional literatures. Your information will provide a platform for future research in disability related issues in Laos. The outcome of this research may contribute to the policy support development to families of a child with ASD in Laos.

Will I be identifiable by being involved in this study?
Once the answers typed up and the assignments have been analysed they will be saved as a file. The original answer paper and/or file will be stored at Flinders University. Any identifying information will be removed and the typed-up file stored on a password-protected computer that only Ms Viengsam Indavong, Associate Professor Caroline Ellison and Dr. Louise Reynolds will have access to. Your comments will not be linked directly to you.



Are there any risks or discomforts if I am involved?
The research anticipates few discomforts from your involvement in this study. You may experience the feeling of stress or discomfort while answering questions related to your feelings and personal experience. You may consider taking following steps:

1. Take a break and a deep breath then come back to the questionnaire again.
2. Seek support from Parent Consultation Unit at AfA to discuss your concerns and/or discomfort at Tel: +856 21 330409.
3. You can also withdraw from the study if you really feel uncomfortable to continue answering questions. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the research team or through research intermediary.
4. You can also contact Flinders University Counselling Service (located in South Australia) at following contact:

Flinders University Counselling Service
If participants who experience emotional discomfort and/or distress will be referred to the Flinders University Counselling Service, please ensure that the following contact details are included in all Information Sheets.

Tel: +61 8 8201 2118
Email: counselling@flinders.edu.au (provide your full name, phone number and student ID in the email and a counsellor will contact you by phone).
Appointments – Monday to Friday; 8:45am to 5:00pm

5. There is no financial impact on you for participating in this study.

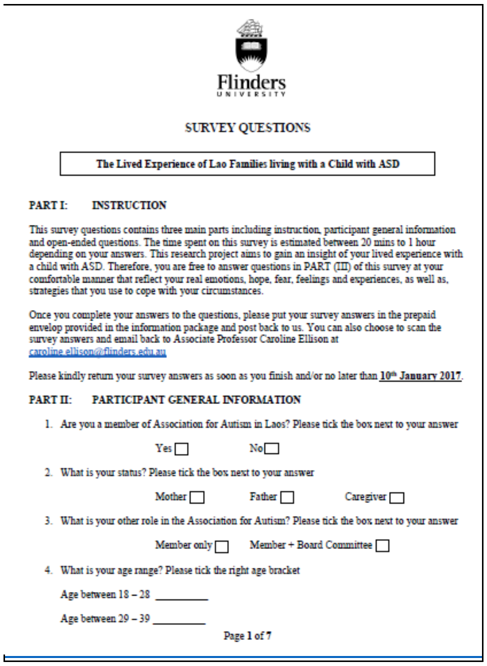
How do I agree to participate?
Your participation will be voluntary and will not affect your membership or your child's involvement at Association for Autism. A consent form accompanies this information sheet. If you agree to participate, please read and sign the form. A questionnaire accompanies this information sheet. If you agree to participate, please read and answer questions describing your experience. You are free to withdraw from the study at any time without effect or consequences.

How will I receive feedback?
Outcomes from the study will be summarised and given to you by the researcher if you would like to see them.

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 Behavioral Research Ethics Committee (Project Number 7431). 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 3: Questionnaires



Flinders UNIVERSITY

SURVEY QUESTIONS

The Lived Experience of Lao Families living with a Child with ASD

PART I: INSTRUCTION

This survey questions contains three main parts including instruction, participant general information and open-ended questions. The time spent on this survey is estimated between 20 mins to 1 hour depending on your answers. This research project aims to gain an insight of your lived experience with a child with ASD. Therefore, you are free to answer questions in PART (III) of this survey at your comfortable manner that reflect your real emotions, hope, fear, feelings and experiences, as well as, strategies that you use to cope with your circumstances.

Once you complete your answers to the questions, please put your survey answers in the prepaid envelop provided in the information package and post back to us. You can also choose to scan the survey answers and email back to Associate Professor Caroline Ellison at caroline.ellison@flinders.edu.au

Please kindly return your survey answers as soon as you finish and/or no later than **10th January 2017**.

PART II: PARTICIPANT GENERAL INFORMATION

1. Are you a member of Association for Autism in Laos? Please tick the box next to your answer

   Yes ☐ No ☐

2. What is your status? Please tick the box next to your answer

   Mother ☐ Father ☐ Caregiver ☐

3. What is your other role in the Association for Autism? Please tick the box next to your answer

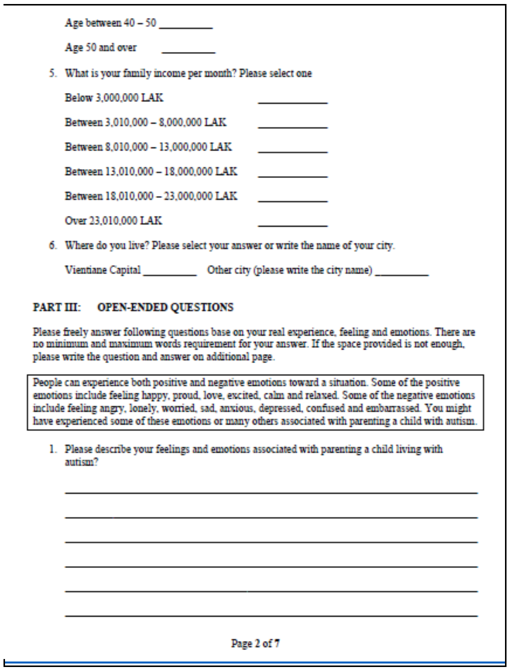
   Member only ☐ Member + Board Committee ☐

4. What is your age range? Please tick the right age bracket

   Age between 18 – 28 __________

   Age between 29 – 39 __________

Page 1 of 7



Age between 40 – 50 __________

Age 50 and over __________

5. What is your family income per month? Please select one

   Below 3,000,000 LAK __________

   Between 3,010,000 – 8,000,000 LAK __________

   Between 8,010,000 – 13,000,000 LAK __________

   Between 13,010,000 – 18,000,000 LAK __________

   Between 18,010,000 – 23,000,000 LAK __________

   Over 23,010,000 LAK __________

6. Where do you live? Please select your answer or write the name of your city.

   Vientiane Capital __________ Other city (please write the city name) __________

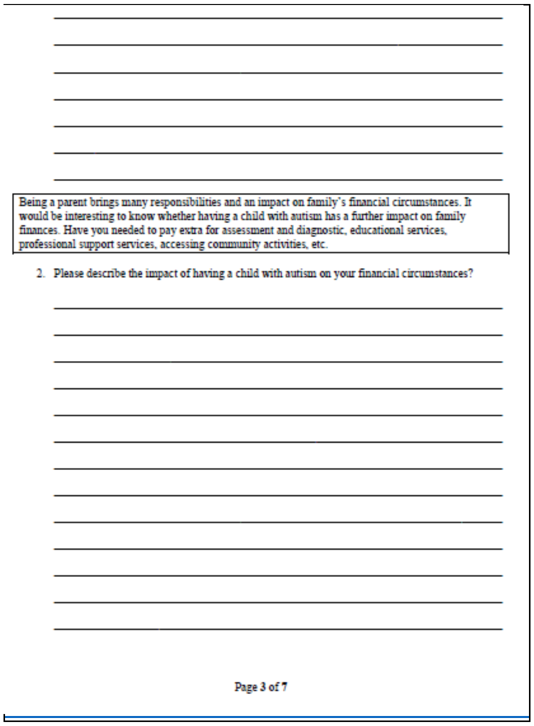
PART III: OPEN-ENDED QUESTIONS

Please freely answer following questions base on your real experience, feeling and emotions. There are no minimum and maximum words requirement for your answer. If the space provided is not enough, please write the question and answer on additional page.

People can experience both positive and negative emotions toward a situation. Some of the positive emotions include feeling happy, proud, love, excited, calm and relaxed. Some of the negative emotions include feeling angry, lonely, worried, sad, anxious, depressed, confused and embarrassed. You might have experienced some of these emotions or many others associated with parenting a child with autism.

1. Please describe your feelings and emotions associated with parenting a child living with autism?

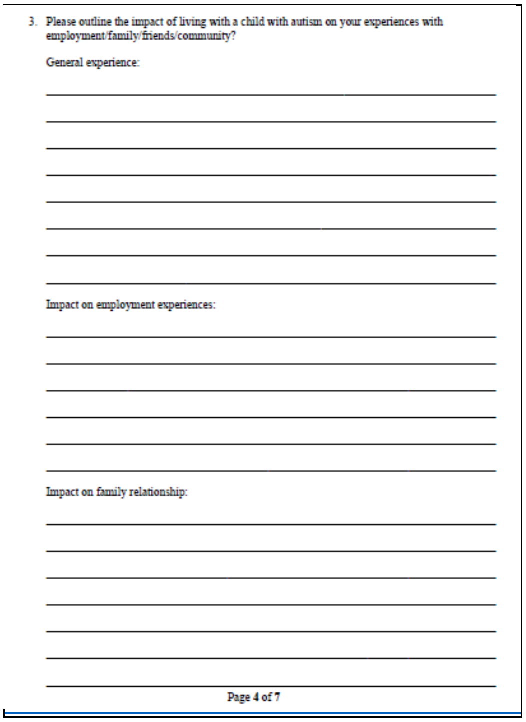
Page 2 of 7



Being a parent brings many responsibilities and an impact on family's financial circumstances. It would be interesting to know whether having a child with autism has a further impact on family finances. Have you needed to pay extra for assessment and diagnostic, educational services, professional support services, accessing community activities, etc.

2. Please describe the impact of having a child with autism on your financial circumstances?

Page 3 of 7



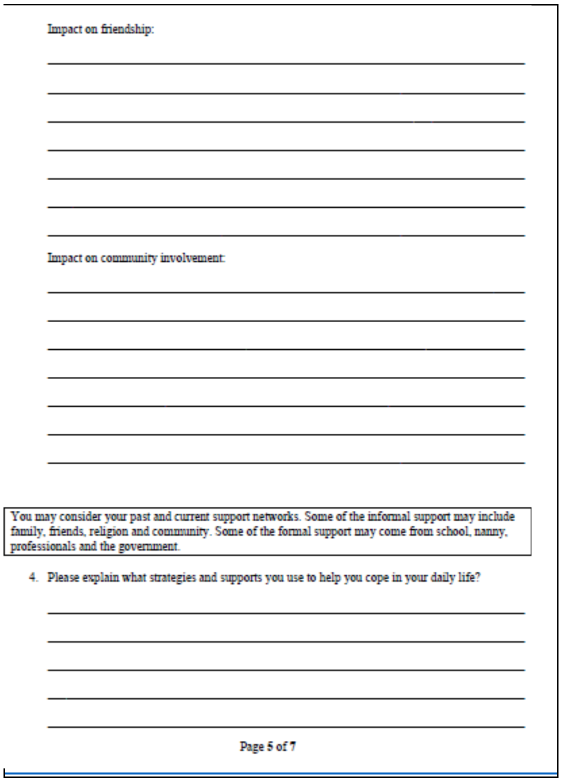
3. Please outline the impact of living with a child with autism on your experiences with employment/family/friends/community?

   General experience:

   Impact on employment experiences:

   Impact on family relationship:

Page 4 of 7



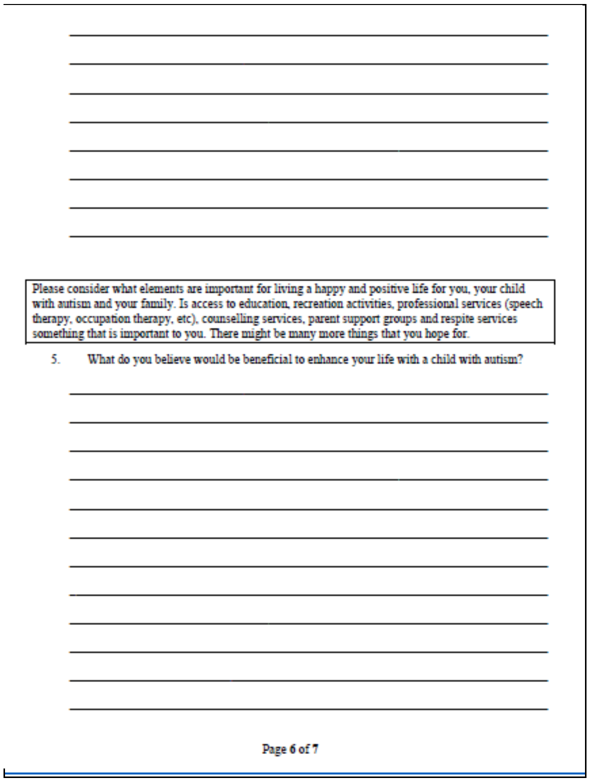
Impact on friendship:

Impact on community involvement:

You may consider your past and current support networks. Some of the informal support may include family, friends, religion and community. Some of the formal support may come from school, nanny, professionals and the government.

4. Please explain what strategies and supports you use to help you cope in your daily life?

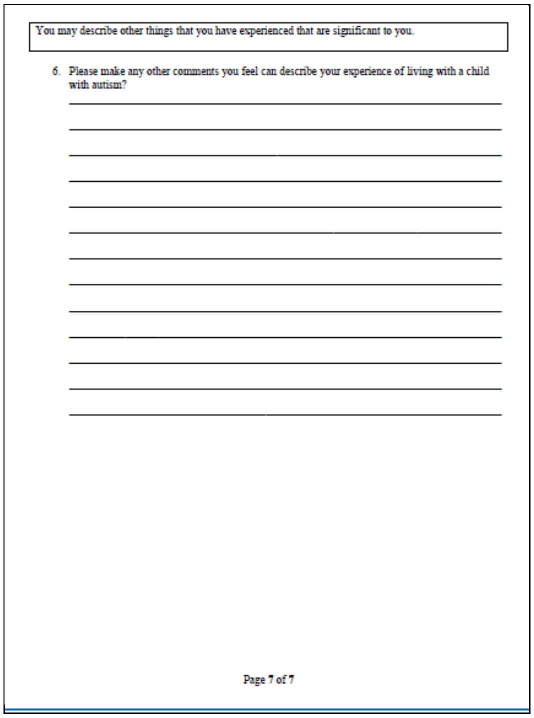
Page 5 of 7



Please consider what elements are important for living a happy and positive life for you, your child with autism and your family. Is access to education, recreation activities, professional services (speech therapy, occupation therapy, etc), counselling services, parent support groups and respite services something that is important to you. There might be many more things that you hope for.

5. What do you believe would be beneficial to enhance your life with a child with autism?

Page 6 of 7

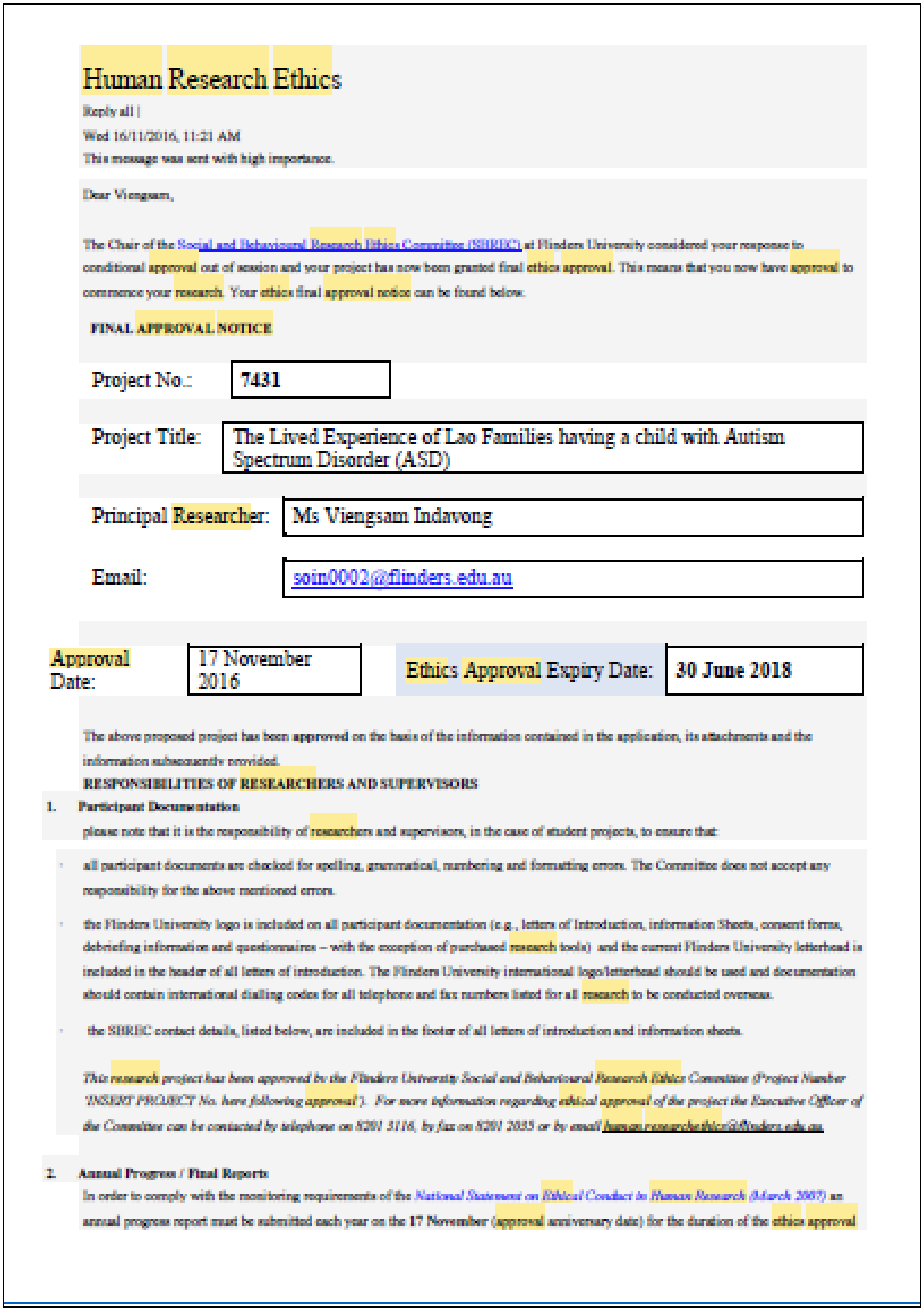


You may describe other things that you have experienced that are significant to you.

6. Please make any other comments you feel can describe your experience of living with a child with autism?

Page 7 of 7

Appendix 4: Ethics Approval Grant



Human Research Ethics

Reply all |

Wed 16/11/2016, 11:21 AM

This message was sent with high importance.

Dear Viengsam,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.: **7431**

Project Title: The Lived Experience of Lao Families having a child with Autism Spectrum Disorder (ASD)

Principal Researcher: Ms Viengsam Indavong

Email: soin0002@flinders.edu.au

Approval Date: 17 November 2016

Ethics Approval Expiry Date: **30 June 2018**

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

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 (March 2007)* an annual progress report must be submitted each year on the 17 November (approval anniversary date) for the duration of the ethics approval

Appendix 5: Research Timeline

Tasks	**Jul-16**	**Aug-16**	**Sep-16**	**Oct-16**	**Nov-16**	**Dec-16**	**Jan-17**	**Feb-17**	**Mar-17**	**Apr-17**	**May-17**	**Jun-17**	**Jul-17**
Research Preparation													
Research Concept	🟪												
Literature Review		🟪	🟪										
Development of Research Proposal			🟪	🟪	🟪								
Ethics Approval Submission		🟪											
Research Proposal Presentation					🟪								
Working with Third Party Recruiter					🟪								
Ethics Approval Granted						🟪							
Survey Package Sent to Laos						🟪							
First 2 Chapters										🟪			
Data Collection													
Third Party Recruiter deliver survey packages						🟦							
Participants return survey answers							🟦						
Data Analysis													
Translation of total 26 return surveys								🟩	🟩				
Content Analysis									🟩	🟩			
File the survey									🟩				
Data Interpretation													
Writing up Thesis										🟧	🟧		
Project Completion													
Draft Thesis submission												🟧	
Final Thesis submission												🟧	
Feedback Received													🟧