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Beyond an Uncertain Future: Vietnamese Parents of Children with Autism Spectrum Disorders and Their Needs for Social Support

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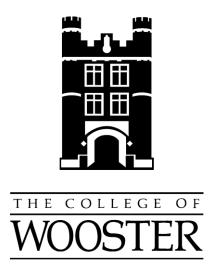khoang17@wooster.edu

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BEYOND AN UNCERTAIN FUTURE: VIETNAMESE PARENTS OF CHILDREN WITH
AUTISM SPECTRUM DISORDERS AND THEIR NEEDS FOR SOCIAL SUPPORT

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ABSTRACT

While Vietnamese parents of children with Autism Spectrum Disorders (ASD) experience great uncertainty and stress about their children's development and adjustment to adult life, they have not received sufficient support. This study aims to identify the specific needs for social support of Vietnamese parents of children with autism. To carry out the study, I conducted ten ethnographic interviews with parents of children with ASD who lived in urban areas within Vietnam. The findings of this study led to four main conclusions. First, the parents' needs for informational, instrumental, and emotional support varied according to their children's age and level of ASD severity. Second, instrumental support was the most desirable type of functional support for the parents. Third, my study discovered the significant role of other parents of children with ASD in providing support for the ten participants. Lastly, the study recognized the parents' high expectations for social support from the Vietnamese government and non-governmental organizations.

Keywords: autism spectrum disorders, social support, uncertainty reduction, Vietnam

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CHAPTER I: INTRODUCTION

Autism Spectrum Disorder (ASD) was recognized in Vietnam during the late 1990s, and the number of diagnosed cases has rapidly increased. The most recent report by the Vietnam Public Health Association estimated 160,000 diagnosed cases of autism in the country as of 2012 and suggested that the number may soon reach to as many as 870,000 cases (Ying, Browne, Hutchinson, Cashin, and Bui 291). Similar to other parents who have a child with autism, Vietnamese parents experience great uncertainty and stress about their children's condition and adjustment to adult life.

Having a sister diagnosed with autism for over four years, I have witnessed the severe pressure and worry experienced by my parents and other parents my family has met in the specialized schools for children with autism. I have also observed over the years that parents often interacted with each other to share their worries, to ask for advice, or to celebrate the improvements made in their children's lives. These interactions actually helped relieve the negative feelings among the parents. In other words, through their interactions, the parents intentionally or unintentionally communicated support to one another. This observation sparked my interests in investigating social support as an approach to provide assistance for the Vietnamese parents who have a child with autism.

Social support aims at improving individuals' well-being via different types of assistance: emotional support, which comforts recipients who are dealing with negative feelings; informational support, which informs recipients of the problem and coping potentials; tangible support, which provides visible assets or physical assistance to help recipients overcome the difficulty; and network support, which widens recipients' network of individual contacts to allow more helpful resources (Cutrona 7; Cutrona, Suhr, and MacFarlane 39). The support that I

observed the parents of children with autism communicating to one another could fall under many of the above support types. For instance, they offered emotional support in the form of encouragement to each other by celebrating the children's progress, and they gave informational support by providing other parents with advice. Even though such social support revealed signs of a promising approach for parents of children with ASD, Vietnamese parents themselves, as well as physicians and other potential support providers, are mostly unaware of the wide variety of potential social support and how to harness its power to better the lives of children with ASD and their families. Therefore, my study aims to explore social support as an approach to assist parents of children with autism. This chapter provides an overview of the study through explanations of its purpose, rationales, and definitions, as well as the method used to carry out the study.

Purpose Statement

This study aims to identify specific needs for social support of Vietnamese parents of children with Autism Spectrum Disorders (ASD). In order to achieve this main purpose, the study will not only examine factors that mediate the parents' needs—which include parental stress of raising a child with ASD in Vietnam and the inadequacy of social support that the parents receive—but also attend to the parents' self-reported request for additional assistance. To carry out this study, I conduct in-depth interviews with ten parents of children with ASD in urban areas within Vietnam.

Rationales

The study is important for three reasons. First, the qualitative method of ethnographic interviews used in this study offers essential insights into the uniquely stressful experience of raising a child with ASD and the demands that parents have for social support. Research in

countries other than Vietnam suggested that parents who have a child with autism often describe negative feelings such as "anxiety," "depression," "hopelessness," "frustration," and "powerlessness." They also express their unending worry about the child's future employment and adjustment to adult life. The extra attention needed for the child with autism, the expensive cost of ASD intervention and treatment services, as well as the lack of awareness and understanding among extended family members worsen the parents' stress (Nealy, O'Hare, Powers, and Swick 193-195 and 197). Past research mostly utilized quantitative methods such as survey interviews or questionnaires to examine the parents' experience and needs for support (Bromley, Hare, Davison, and Emerson 412; Hartley and Schultz 1636; Siklos and Kerns 923; Zablotsky, Bradshaw, and Stuart 1380). While these methods helped researchers obtain statistical measurement and categorization of the parents' requests for support, ethnographic interviews used in my study give the parents more freedom to provide richer context and personal narratives on their lived experience.

Second, this study contributes to the limited research on social support for parents of children with ASD in Vietnam. Although researchers in other countries such as the United States, the United Kingdom, France, and Canada have been studying social support for decades (e.g., Albrecht and Goldsmith 263; Bromley, Hare, Davison, and Emerson 420; Canary 413; Cohen and Syme 3; Siklos and Kerns 928; Thoits 420), the topic remains largely unexamined in Vietnam. Only a few studies in Vietnam concerned issues related to social support, such as social and economic support for HIV-positive mothers (Oosterhoff, Nguyen, Pham, Wright, and Hardon 162); support for war veterans with traumatic stress disorder (King, King, Keane, Fairbank, and Adams 420; Korinek and Teerawichitchainan 1478; Irving, Telfer, and Blake 465); support for manufacturing employees who suffered from depression (Pham 950); and

support for pregnant women who were opiate users (White and Oosterhoff 4). One prior study assessed social support for Vietnamese mothers of children with cognitive disabilities (Park, Glidden, and Shin 38). Regarding the topic of social support and ASD, three studies discussed the prolonged stress that Vietnamese parents endured when raising a child with autism (Ha, Whittaker, Whittaker, and Rodger 278; Motchan 28; Ying et al. 288). However, only one of these studies suggested a method to address informational needs through the distribution of an ASD information book for parents after the diagnosis (Ying et al. 288). Similar to other parents of children with ASD, Vietnamese parents face many difficulties that call for social support. In addition to their limited knowledge about autism, the parents have little access to and options for intervention programs for their children; they also suffer from emotional and financial burdens, as well as social discrimination against their children with ASD (Park, Glidden, and Shin 40; Ha et al. 280-281). Despite the variety and severity of stress experienced by Vietnamese parents of children with autism, no other study has investigated the parents' desires for support by asking the parents directly. Instead of assuming the parents' needs, this study wants to give voice to the parents and to understand the parents' experience and wishes for social support from their points of view.

Last but not least, my study not only informs support groups about the desired social support of Vietnamese parents of children with ASD, but also calls for the involvement of the Vietnamese government in helping these parents. The findings of my study should prove beneficial for support groups to adjust their course of actions to meet the parents' needs. For smaller support groups with fewer resources or less funding, my study will suggest several options for support that the financially restricted groups would be able to offer. For example, the groups may focus on either emotional or informational support for the parents. Additionally, my

study draws attention to the existing limitations of the kinds of support that Vietnamese parents already received. Noticing these problems, support groups could direct their resources to areas that need improvement. Furthermore, this study hopefully can encourage positive changes in Vietnamese government policies to grant children with ASD and their parents the benefits that they need to flourish. An acknowledgement of the needed yet unavailable support for Vietnamese parents may urge the government to provide funding for support groups, or to create a committee that advise those groups on effective methods to support parents.

Definitions

Two key terms that are important to understand this study include: social support and Autism Spectrum Disorders. *Social support* is assistance provided by others to individuals in need through interactions within social networks; social support aims at promoting recipients' physical, mental, and emotional well-being (Cohen and Syme 4; Hobfoll and Stephens 455; McLeroy, DeVilles, DeVilles, Kaplan, and Toole 411). *Autism Spectrum Disorders (ASD)* refers to a range of neurological disorders that cause impairments in verbal and nonverbal communication. *ASD* is identified with "restricted, repetitive and stereotypical" interests and behaviors that lead to patients' difficulties in social interactions and relations (Deris and Di Carlo 52; Nealy et al. 187; Vakil, Welton, O'Connor, and Kline 322).

Method

This study utilizes a qualitative method of ethnographic interviews to determine the characteristics of social support desired by Vietnamese parents of children with ASD. In ethnographic interviews, researchers engage in in-depth conversations with participants to collect and then analyze detailed, descriptive answers that disclose respondents' emotions, opinions, and experiences with an issue or event (Frey, Botan, Friedman, and Kreps 285-287). I use this

method to interview ten Vietnamese parents of children with ASD who live in urban areas within the country. In the interviews, I ask the parents to describe their experience of raising a child with ASD, to list and evaluate the social support that they receive, and to explain types and sources of additional support that they desire.

Conclusion

Chapter I has introduced a purpose statement that explains the goal of my study, three rationales that justify the significance of this study, definitions of key concepts, and the method used to conduct the research. My study aims to examine the needs for social support of Vietnamese parents of children with ASD. The study sheds light on the stressful experience of raising a child with autism in Vietnam, parents' evaluation of social support that they receive, and parents' request for additional support. This study is important because it not only provides an ethnographic perspective on the parents' experience and the kinds of social support that they desire, but also adds to research on the topic in the specific context of Vietnam. Moreover, findings of this study could guide support groups in their future actions to fulfill the parents' needs for social support. The findings of this study may also encourage the Vietnamese government and non-governmental organizations to offer funding and guidance for support organizations to enrich the lives of children with autism and their families. To carry out this study, I utilized a qualitative approach to conduct ethnographic interviews with ten Vietnamese parents of children with autism in urban areas within Vietnam. Chapter II will review past scholarship on the topic to provide a foundation for this study.

CHAPTER II: LITERATURE REVIEW

An in-depth examination of previous research is crucial for establishing the context of my study on the needs for social support of parents of children with autism. In this review of past literature, I will first discuss Uncertainty Reduction Theory as a basis for the study of social support and its positive effects on individuals' well-being. Then, I will examine social support and its connection to uncertainty reduction, as well as useful approaches to studying social support. Lastly, I will turn to Autism Spectrum Disorders (ASD), parental stress, and social support for parents of children with ASD.

Uncertainty Reduction Theory

Berger developed Uncertainty Reduction Theory (URT) to explain how individuals interact and form relationships with strangers. URT assumes that when individuals first meet someone, they have little knowledge about the person's beliefs and preferences. Therefore, their primary concern is to reduce uncertainty about the person. Individuals do so by gaining knowledge about the interaction partner in order to explain and predict the person's behaviors and to respond to those behaviors in a suitable manner (Bacon 6-7; Berger 41-42).

There are three main factors that motivate individuals to reduce their uncertainty about others. First, uncertainty reduction is essential when individuals expect future interactions with the other partner (Berger 46; Simmel 15). A first-year student who will meet her roommate for the first time wants to reduce uncertainty about the roommate before their first interaction. The student may seek information about the roommate's hobbies or interests by looking at her Facebook profile. This information may give clues to topics that the student should talk to her roommate about in order to express shared interests and establish the foundation for a good relationship with the roommate. Second, in addition to expectations of future interactions,

incentive values–or potential rewarding outcomes of interaction with another– prompt individuals to reduce uncertainty (Berger 46; Simmel 17). A woman may meet a representative of her favorite company at a career fair, and recognize this contact could lead to a future position with the company. The potential for a rewarding outcome encourages the person to gain more knowledge about the representative's current position as well as expectations of job candidates at the organization. Last but not least, individuals want to reduce uncertainty about interaction partners if the partners' behaviors violate social norms or personal expectations (Berger 46; Simmel 15). A student may notice that when his mother meets his girlfriend for the first time, she asks the girlfriend many questions and does not smile throughout the conversation. Those reactions are quite different from the mother's normal behaviors when meeting her son's friends. As a result, her son feels the need to find out the reasons behind his mother's reactions.

Individuals can adopt passive, active, or interactive strategies to reduce their uncertainty about an interaction partner. Passive strategies include gathering information about the target person through observation (Berger 46; Simmel 18). A person may learn more about a new classmate by observing the classmate's behaviors and interactions with other students in school settings such as classrooms and the dining hall. Individuals can also utilize active strategies to gain knowledge about a partner through a third party such as social networking sites. For example, a girl may check the partner's Facebook and Instagram to learn more about the partner's appearance or interests before going on a date with the partner. Last but not least, individuals can use interactive strategies to seek information through direct face-to-face interaction with the target person (Berger 46; Simmel 18). The girl in the previous example may go on the date and ask her partner directly about his personal beliefs, interests, and hobbies. However, individuals not only can experience uncertainty about a stranger, but also about an

event when they can neither understand its meaning nor predict possible outcomes due to the lack of information (Mishel and Braden 48; Simmel 15). Thus, individuals facing the unexpected event feel unsure about how to react adaptively to control its consequences. This uncertainty can generate negative feelings such as stress and anxiety for individuals (Berger 54). A person may discover that he has a dangerous chronic condition that could lead to a stroke. This shocking news causes the person to feel uncertain about intervention, therapy, or medication that he should take to deal with the problem. Another example is a sudden change in a person's employment position. The person may be in charge of new responsibilities and work with a new team whose working styles are greatly different from those of her old co-workers. This change in job position thus generates the person's uncertainty about her adjustment to the new working environment in order to perform well. This type of uncertainty is mostly related to social support. The following section will explain the concept of social support and the effects of social support on uncertainty reduction.

Social Support

Social support is assistance provided to individuals in order to facilitate their ability to cope with stressful events and to promote their physical, mental, and emotional well-being (Cohen and Syme 4; Hobfoll and Stephens 455; McLeroy, DeVilles, DeVilles, Kaplan, and Toole 411; Pierce, Sarason, and Sarason 173). Individuals give and receive social support through verbal and nonverbal interactions occurring within their social networks (Albrecht and Adelman, "Communicating Social Support" 19; Leatham and Duck 3). Social support can come in the form of visible assistance such as physical, material, and monetary aid; it also aims to offer a sense of love, care, encouragement, recognition, acceptance, or connection and attachment to groups or supportive networks (Albrecht and Goldsmith 265; Hobfoll and Stephens 455).

Moreover, social support acts as a buffer against stresses (House and Kahn 105; Israel 70). Albrecht and Adelman specified the effects of social support, claiming that social support "reduces [recipients'] uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life experience" (Albrecht and Adelman, "Communicating Social Support" 19).

Social Support and Uncertainty Reduction

Uncertainty reduction is inherent in social support because the primary goal of supportive exchange is to reduce or manage individuals' uncertainty about a stressful experience (Scott, Martin, Stone, and Brashers 397). According to Albrecht and Adelman, support recipients consider themselves helped only when the received support reduces their uncertainty about the event and allows them to make sense of the difficult situation (Albrecht and Adelman, "Social Support" 21).

URT is useful for the study of social support because the theory can explain which support providers individuals evaluate as helpful. Albrecht and Adelman claimed that individuals prefer receiving support from those they feel less uncertain about ("Social Support" 20). A person who experiences marital relationship dissatisfaction will likely seek advice from close contacts such as family members and best friends rather than from professional colleagues. Additionally, individuals perceive support from others who have had similar experiences as more helpful because the support providers better understand the problems, thus having credible knowledge to define the situation, offer help, or give suggestions for coping strategies to control the outcome of the event (Albrecht and Adelman, "Social Support" 17, 20). Social support coming from this source also reduces a person's uncertainty by normalizing the stressful experience. In other words, support providers encourage recipients to believe that "they are not

the only one" facing the situation in order to eliminate the recipients' feelings of isolation and uncertainty (Scott et al. 397-398).

Another assumption that links URT with social support is that support providers may face uncertainty about the suitability of the support that they can offer. However, if uncertainty reduction in supportive relationships is reciprocal, or in other words, both support providers and recipients have their needs for uncertainty reduction met, the relationships will become more stable and sustainable (Albrecht and Adelman, "Social Support" 22).

Positive Effects of Social Support on Uncertainty Reduction. Prior research has shown that social support allows a person to reduce or to manage uncertainty about a stressful situation. First, social support reduces a person's uncertainty by providing more information to eliminate the ambiguity and unpredictability of a stressful event (Albrecht and Adelman, "Social Support" 17; Brashers, Neidig, and Goldsmith 323; Donovan, LeFebvre, Tardrif, Brown, and Love 434; Mishel and Braden 56). When a person moves to a new town, support from neighbors that informs the person of essential local businesses such as markets and shopping centers will facilitate the person's adaptation to the new living environment. Social support can also reduce uncertainty by validating a person's coping action (Brashers, Neidig, and Goldsmith 314-315). An intern who experiences harassment in the workplace may want to report the incident to a manager. Support from co-workers confirming that such a response is needed will increase the intern's confidence in her coping action.

Social support also assists uncertainty reduction by promoting a person's relational security. Receiving support from others reduces a person's uncertainty about the intimacy and stability of relationships with the support providers (Brashers, Neidig, and Goldsmith 313; Scott et al. 397). When a person worries about her grades at school and receives expected support from

her best friend, that support could both alleviate the person's concerns and affirm the relationship between her and her friend. Recurrent social support also reduces a person's uncertainty about the strength of his relationship with the supporter, as well as the availability of support in the future (Scott et al. 397). If a researcher receives funding several times from an organization to conduct research, he may feel confident that the relationship between him and the organization is strong and that he can expect the organization's sponsorship for his future research.

Another way through which social support facilitates uncertainty reduction is by encouraging perspective shifts. Support providers either transform recipients' negative perceptions towards the stressful event by reframing the situation to make it non-threatening, or persuade support recipients to face reality and accept uncertainty as normal. In the case of patients with chronic illnesses, support providers may encourage these patients to view uncertainty as an opportunity to maintain hope and as a motivation to seek care (Brashers, Neidig, and Goldsmith 315; Scott et al. 398).

Nevertheless, Brashers, Neidig, and Goldsmith argued that social support may help manage rather than reduce recipients' uncertainty by withholding information about the stressful event. For instance, support providers of patients with chronic illnesses such as heart disease or cancer may hide information relating to the patients' health conditions or may avoid discussing illness-related issues in order to relieve the patients' negative feelings (Brashers, Neidig, and Goldsmith 311).

Negative Effects of Social Support on Uncertainty Reduction. Despite its potential positive effects on uncertainty reduction, social support may result in negative consequences including creating extra uncertainty for support recipients and placing stress and anxiety on support providers. Social support may cause recipients to realize their lack of control over the stressful situation and to question their ability to deal with stress. Support recipients may see themselves as

incompetent and dependent on the support providers (Brashers, Neidig, and Goldsmith 316; Goldsmith and Parks 116; La Gaipa 138; Scott et al. 398). Social support, therefore, creates a "problem of impression management" for recipients since receiving support from others decreases the recipients' sense of power and autonomy. Moreover, disclosing their personal weaknesses to support providers can make the recipients feel vulnerable (Albrecht and Adelman, "Social Support" 24).

Other than its negative impact on recipients' perceptions of personal independence and competence, social support may also cause support seekers to experience uncertainty about the responses that they may get from support providers (Albrecht and Adelman, "Social Support" 25). Individuals worry that they will receive negative reactions from others such as rejection, avoidance, or discrimination (Brashers, Neidig, and Goldsmith 319). Recipients may notice the obligations that come with the support and feel unsure about how to act on it so that they will not disappoint the providers (Scott et al. 399). For example, despite studying with a tutor, a student still has difficulties with his class assignments. The student experiences uncertainty about ways to boost his academic improvement since he does not want to disappoint the tutor who spent hours helping him with the assignments. Furthermore, support recipients may face relational uncertainty if the received support is incompatible with the relationship between providers and recipients. Sometimes, support recipients may receive greater support from individuals with whom they are not close while gaining less satisfactory support from intimate others such as families and friends (Scott et al. 298). A transgender person may not gain full acceptance from family and friends due to stereotypes, yet receive encouragement and reassurance from members of an online discussion forum with whom ze has had no direct contact. Thus, the incompatibility of received of support and the person's closeness to the support providers makes the person feel uncertain about relationships with the providers.

The social support process may not only create extra uncertainty for support seekers, but

also cause support providers stress and anxiety. Consequently, this risk can limit the amount and quality of support that providers are willing to offer (Albrecht and Adelman, "Social Support" 23; Brashers, Neidig, and Goldsmith 316; Goldsmith and Parks 116; Pierce, Sarason, and Sarason 179; Scott et al. 399). In their study, Pierce, Sarason, and Sarason argued that family members of individuals with chronic illnesses also feel stressful and anxious, so they may orient their behaviors towards reducing their own stress first before helping the patients (179).

The positive and negative effects that social support may have on uncertainty reduction creates a dilemma for support seekers. In order to overcome this dilemma, support seekers can adopt several strategies to maximize the positive outcomes of social support while minimizing the negative consequences. One strategy is to wait for potential providers to offer their support. As a result, the support seekers can receive support without asking for it and thus avoid portraying themselves as incompetent individuals who are in need of assistance. In order to prevent unhelpful support, individuals may ask for support selectively from those whom they believe will give the most effective assistance (Brashers, Neidig, and Goldsmith 325; Scott et al. 400-401). However, if unhelpful support is unavoidable, support recipients may cope by reframing the support providers' attempt to focus on their good intentions rather than their poor supporting skills (Scott et al. 400-401). A person may seek advice from her friend to resolve romantic relationship conflicts. Although her friend may ask too many questions and annoy her, the person will choose to perceive these questions as the friend's sincere concern and willingness to help. In the next sections, I will discuss the communicative nature of social support, different approaches to studying social support, the integration of these approaches, and personal and environmental factors that influence the support process.

Social Support as a Communicative Process

Social support emerges from human social interactions (Leatham and Duck 3). It is not simply the transfer of supportive resources from providers to receivers; rather, social support is a communicative process that involves "interactive influences among intrapersonal, interpersonal and situational contexts" (Pierce, Sarason, and Sarason 189). The support that a person receives may vary depending on the relationship between that person and the support providers. For example, support from an athletic coach will not be similar to the support from a close friend. Social support is also different based on the situation that potential recipients experience. A first-year college student might ask for more support than an upper-class student who is already familiar with the campus services and academic curriculum. According to scholars, social support is a rhetorical, rather than a mechanical, process in which speech acts and communicative events occur to convey assistance that resolves recipients' needs (Albrecht and Goldsmith 268; Goldsmith, "The Role of Facework" 35; Goldsmith and Fitch 456). Through communication, support providers and receivers discuss the problem, seek information to understand the situation, find suitable solutions, and offer and obtain support (Wright, Sparks, and O'Hair 93). Therefore, in order to understand the support process, it is important to examine the way individuals discuss, negotiate, and deliver support through their interactions (Leatham and Duck 19).

Social support is also a symbolic process because participants' interpretation of supportive acts and interactions determines the adequacy of support outcomes (Cohen and Syme 12-13; Goldsmith and Fitch 455). However, a one-time conversation or act of support is insufficient for individuals to assess the received assistance. Rather, routine and recurring interactions form a basis for individuals' judgments on whether an act or relationship is

supportive (Cutrona, Suhr, and MacFarlane 31-32; Leatham and Duck 3). Based on a student's past experience of meeting weekly with her advisor and receiving helpful advice that addresses her academic concerns, the student may evaluate her advisor's support and the student-advisor relationship as highly supportive. Besides the recurrence of interactions, communicative patterns also play a crucial role in determining how and why an act may bring about supportive effects (Goldsmith and Fitch 473). These patterns include support recipients' and providers' language styles, the content and order of supportive messages, and the providers' skills in conveying these messages (Goldsmith, *Communicating Social Support* 150; Goldsmith, "The Role of Facework" 32). For example, a doctor's clear explanation of a medical treatment process that avoids complex technical terms enables the patient to understand the given information more easily, thus making the intended support effective.

<div align="center">**Different Approaches to the Study of Social Support**</div>

Scholars have studied social support from both structural and functional approaches. While the structural approach concerns the structure of social networks and the interconnection between relationships of network members, the functional approach examines the availability and efficacy of particular functions that social networks provide (Hall and Wellman 35; House and Kahn 84-85).

The Structural Approach. The structural, or network analysis, approach focuses on the structural aspects of social networks in which the support process occurs (Hall and Wellman 35; House and Kahn 91; Pierce, Sarason, and Sarason 174). Researchers define social networks as groups of individuals connected to one another by one or more types of relationship. Social networks provide context and means through which members construct and maintain social identity, as well as give and receive social support (Hall and Wellman 25; Walker, MacBride,

and Vachon 35; Wright et al. 95). For instance, the group of individuals a person chooses to be friends with tells a lot about who she is and influences her habits and outlook on the world. The close relationship among members of this friend group also enables the exchange of emotional support such as the sharing of feelings and experiences. Another example is a young man's membership in an environmental organization, which implies an aspect of his identity in the form of his dedication to environmental protection. The frequent interaction and cooperation with other organizational members shape his perspectives and acts with regard to environmental issues. Members of the organization give support to and receive support from one another through their completion of distributed tasks to accomplish shared goals.

The structural approach examines the quantitative and qualitative properties of social networks that mediate the flow of supportive resources to network members and also studies the effects of that support (Hall and Wellman 33; Pierce, Sarason, and Sarason 187). The quantitative properties include size, or the number of contacts in social networks, and density, or the number of actual direct connections out of all potential connections within a network (Hall and Wellman 28; Israel 67; Walker, MacBride, and Vachon 35). Two networks could have the same size but a different level of density. A family network of 20 people could have a higher density than a network of 20 students in a classroom because all of the family members know, contact, and connect to one another, while only half of the students may actually make direct connections and independent contacts with one another. The qualitative properties of social networks consist of dispersion, or the ease of connection as a result of geographical proximity among members, and intensity, or the strength of connections as a result of frequent interactions among members (Albrecht and Goldsmith 268- 269; House and Kahn 86; Israel 65; Walker, MacBride, and Vachon 35). A network of individuals who live in the same neighborhood could

have a high dispersion because it is easy for the neighbors to walk a few steps to visit each other and interact face-to-face. This network could have a high intensity if the neighbors spend a great amount of time together and form a strong bond with one another. The neighbors may help each other with housework, participate in community projects together, and visit each other on family holidays. The qualitative properties of a network also include homogeneity, or the level of shared demographic characteristics, personalities, or communication styles among network members (Albrecht and Goldsmith 268- 269; House and Kahn 86; Israel 65; Walker, MacBride, and Vachon 35). Besides geographical proximity, high levels of homogeneity could be another factor that brings individuals together to form relationships. As we may see, best friends or romantic partners usually share particular characteristics, perspectives, and lifestyles.

The structural approach also examines the qualitative content or meaning that network members assign to their relationships (Albrecht and Goldsmith 268-269; House and Kahn 86; Israel 65; Walker, MacBride, and Vachon 35). A man may consider a woman his close friend, while the woman sees the man only as a professional colleague. Other qualitative properties of social networks include the durability or stability of connections, the reciprocity of relationships, and the multiplicity of supportive roles that a network member plays (Albrecht and Goldsmith 268-269; House and Kahn 86; Israel 65; Walker, MacBride, and Vachon 35). While durable and stable connections sustain for a long time without sudden changes or crises, reciprocal relationships require an equal interchange of affection or help among partners. The multiplicity of support roles indicates the different types of support that a network member could provide at the same time. One's parents may play the roles of both financial supporters and caregivers.

Based on the sources from which support arises, the structural approach categorizes social support into informal and formal support. While the former refers to support provided by

family members, friends, acquaintances, or neighbors, the latter describes support given by professionals and specialists. Formal providers in business contexts would include supervisors and co-workers while formal support providers in health-related contexts would be clinicians, doctors, or nurses (Canary 414-415). According to Cohen and Syme, certain sources of support are more relevant than the others in particular situations, too. The authors gave an example to illustrate the argument, claiming that individuals who are looking for a new position may consider formal support from their current supervisors or colleagues more helpful than informal support from a friend or spouse (Cohen and Syme 10). However, if these individuals are in need of stress relief, they might find informal support from romantic partners, close friends, or family members, who understand them better, more beneficial.

House and Kahn claimed that the structural approach is useful to the study of health and illness behaviors "where [recipients'] access to information and providers of care is crucial" (91). Through an analysis of social networks, the structural approach provides helpful information to develop strategies or programs that either create new supportive networks or enhance existing ones (Israel 72-73). However, in order to avoid bias, researchers should evaluate support from multiple standpoints; they should consider the perspectives of support recipients, providers, and other network members (Pierce, Sarason, and Sarason 187).

The Functional Approach. Rather than focusing on the structural aspects of social networks, the functional approach sees social support as specific functions that social networks provide (House and Kahn 85; Pierce, Sarason, and Sarason 177). According to McLeroy et al., this approach not only specifies and differentiates the concept of social support, but also examines the relationship between types, amount, and efficacy of support and the structure of networks in which the support arises (McLeroy et al. 411).

a. Five Types of Functional Support. The functional approach categorizes social support into emotional, informational, tangible or instrumental, appraisal or esteem, and network support. Emotional support involves verbal or nonverbal expressions of love, trust, care, empathy, and encouragement that aim to alleviate recipients' negative feelings and motivate their positive ones (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). An individual may give emotional support to his friend who breaks up with a romantic partner by staying with the friend, listening to her empathetically, or offering her a hug. Support providers may also offer emotional support by simply providing opportunities for stressed individuals to express their feelings (La Gaipa 125). La Gaipa asserted that emotional support is the most appreciated type of support among people who are recently diagnosed with an illness (125). Likewise, House and Kahn considered emotional support a top priority in the support process because it has the strongest connection to recipients' health through both direct and buffering effects on stresses (House and Kahn 105).

The second type of social support, informational support, includes needed information, suggestion, guidance, or advice for recipients (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). For example, a doctor may give a patient information about his illness and advice on medications or interventions. Tangible or instrumental support refers to goods, services, financial aid, labor, or time that are essential for recipients to complete a task successfully (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). Charities provide tangible support to victims of natural disaster by sending money, clothes, food, and medicines to help the victims sustain their lives. Another type of functional support is appraisal or esteem support, which provides reassurance or affirmation of self-worth, or encourages a sense of self-competence by giving

positive feedback on individuals' capabilities to cope with stresses (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). For instance, a coach's praise for athletes' prior achievements may motivate their confidence in winning the next season. The last type of functional social support is network support, which promotes social integration or group memberships that allow individuals to socialize with and receive extra support from people who share their interests or concerns (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). An example of network support would be the formation of an association that brings international students at an American college together in order to share and discuss solutions for their difficulties of living in the States.

　　b. The Optimal Matching Model. The functional approach suggests an appropriate match of types of support to individuals' specific needs (Pierce, Sarason, and Sarason 177). Cutrona proposed the Optimal Matching Model that allows support providers to identify proper types of support to help recipients overcome stressful events effectively (4). The model suggests two dimensions of a stressful event: controllability and life domain. In uncontrollable events, neither the affected individual nor the support provider can prevent the negative consequences. Therefore, it is better for the support provider to offer emotional support that helps the affected person recover from negative feelings (Cutrona 8). Families of patients in the last stage of cancer may understand that they cannot prevent the patients' deaths; thus, the families may give affectionate support to the patients by showing extra care and concern or planning small family vacations for the patients to spend more time with their beloveds. While emotional support is an optimal match for uncontrollable events, informational, instrumental, and tangible support are more suitable for controllable situations. Since individuals in controllable events are able to lessen or even eliminate the negative consequences, support that encourages such actions will

show the best results (Cutrona 8). Students who are stressed about the workload at school

illustrate a situation in which individuals face controllable stressful events. The students would

need support that directs their future actions to resolve the situation. Thus their professors could

give them advice on time management strategies or learning tips. Controllable events also call

for esteem support that increases recipients' confidence in their ability to overcome the situation

(Cutrona 8). For example, the professors may give encouragement to motivate the students to

adopt new strategies and improve academic achievements.

The second dimension of stressful events is life domain, which includes "assets,

relationships, achievement, and social roles" (Cutrona 8). The loss of any life domain factor

leads to a demand for suitable types of support for replacement. If there is a loss of assets such as

material resources or physical capabilities, tangible support is the appropriate coping option

(Cutrona 8-9). A student who cannot afford his education will need tangible support such as a

loan or financial aid. Conversely, a loss of intimate relationships or social attachments requires

emotional support (Cutrona 10). A person who loses her parent will need expressions of empathy

and care from other family members and friends to overcome the pain and grief. A loss of

achievement such as a student's lowered academic performance or class ranking calls for esteem

support to reassure the student of his competence and motivate him to get back on track. Last but

not least, a loss of membership or a threat to social roles needs network support (Cutrona 10).

For instance, a person who loses her job would ask for contacts of potential employers.

However, Goldsmith has criticized Cutrona's Optimal Matching Model of social support.

The author claimed that Cutrona's model establishes a fixed measurement that oversimplifies the

stressful situation experienced by support recipients (Goldsmith, *Communicating Social Support*

83). An optimal match between types of stresses and types of support is insufficient to guarantee

the efficiency of given support because it ignores other factors such as the relationships between support providers and recipients, recipients' skills in coping with stress, and providers' skills in giving support. While Cutrona's model identifies suitable types of support based on particular demands that may arise from the situational context, the model attends to only two dimensions of the situation and neglects many other facets. For instance, it fails to address how communication between participants of the support process depicts the stressful situation through the use of words and conversational styles, or the emphasis on certain aspects of the situation over the others in their messages (Goldsmith "The Role of Facework" 34; Goldsmith, *Communicating Social Support* 84, 113-114).

    c. Critique of the Functional Approach. In response to the drawbacks of the Optimal Matching Model, Goldsmith suggested coherence as another essential factor that contributes to the effectiveness and situational variability of social support (*Communicating Social Support* 113). According to Pierce, Sarason, and Sarason, the functional approach often assumes coherence in support transactions. The approach expects that support providers and recipients will always agree with each other on potential supportive provisions, and that the actual support exchange reflects this agreement (Pierce, Sarason, and Sarason 179). Nonetheless, the study by Lehman, Ellard, and Wortman concluded that providers frequently fail to provide support that recipients consider helpful, and even if they both agree on the preferred supportive solutions, their actual behaviors may not reflect the planned actions (Lehman, Ellard, and Wortman 442-446). Pierce, Sarason, and Sarason suggested a variable–supporting goals—that explains the above incoherence based on the idea that individuals evaluate the effectiveness of support by judging whether it satisfies set goals (185). The authors argued that support providers and recipients may have very different perspectives on what these goals should be (Pierce, Sarason,

and Sarason 185). A student who needs help on a math assignment may consider support from her tutor effective if the support satisfies her short-term goal of solving the current math problems. However, the tutor, the support provider, aims for a long-term goal of providing supportive instruction that allows the student to solve similar math problems in the future. These different goals lead to different evaluations of given support.

Thus, in order to avoid these discrepancies and to make the provided support effective, Goldsmith emphasized the existence of coherence between providers' and recipients' understanding of the situation and potential solutions (*Communicating Social Support* 113). Without this coherence, providers and recipients may assess a stressful event differently. Support providers may think that a stressful situation is uncontrollable while the recipients consider it controllable. Their conflicting opinions may lead to disagreement on the preferred types of support and coping strategies, thus impeding the progress of the support process. It is no less important to have coherence between the actual support demands and the demands that the providers and recipients co-construct through conversations (Goldsmith, *Communicating Social Support* 113). This coherence simply means that the demands which providers and recipients communicate to each other should match the actual needs of the recipients. Last but not least, Goldsmith stressed the significance of coherence between the provided support and the provider's view of the stressful situation (*Communicating Social Support* 113). A person may understand that because her best friend is feeling lonely, she should come to see the friend. However, what she actually does may conflict with her interpretation of the friend's need for support. Instead of visiting the friend, the person may choose to give emotional support through a phone conversation since it takes her less time and effort. The inconsistency between the person's assessment of the situation and her actual support act may reduce the effectiveness of

the provided support.

Another assumption of functional support is that the effectiveness of support increases as the amount of received support increases (McLeroy et al. 410). Nevertheless, a study by McLeroy et al. challenged the generalizability of this assumption. This study concluded that the increase of instrumental support has negative effects on the physical recovery of stroke patients (McLeroy et al. 395). McLeroy et al. defined instrumental support as assistance for stroke patients in daily self-care activities such as walking, eating, bathing, and dressing (399). The research showed that the increase of received instrumental support led to a decrease in patients' daily living performance score. In contrast, a pause in the provision of instrumental support resulted in patients' improved ability to do daily self-care activities (McLeroy et al. 406). McLeroy et al. suggested two reasons for this negative correlation: (1) instrumental support undermines patients' motivation to do daily tasks themselves since the support providers already help them; (2) instrumental support impedes patients' confidence in their recovery since the patients interpret constant instrumental support as evidence of their permanent inability to care for themselves (408).

Negative outcomes resulting from increased network support also counter the assumed positive correlation between the amount and the effectiveness of support. Network support, which provides more social contacts to recipients, not only increases the amount of received supportive resources, but may also result in an increase of conflicting demands from additional network members that worsens the stressful situation (Cohen and Syme 12). As a person grows up, his network of friends may grow in size to include friends from high school, college, and the workplace. The extended network leads to demands from different friend groups who all want the person to spend time with them. Thus, the person may feel stressed because he has to divide

and arrange his limited time to satisfy the needs from many different friend groups who are part of his social support network.

   d. Barriers to Functional Support. Researchers have discussed several barriers that discourage individuals from giving or receiving support. La Gaipa claimed that support providers' failure to assess the problem adequately may result in improper and unappreciated advice given to recipients (124- 125). Without a careful examination of the reasons behind a student's poor academic performance, an academic counselor may conclude that the student has learning disabilities and advise her parents to send their child to special programs for diagnosis and treatment. Due to this hasty conclusion, the parents may not find the counselor's advice persuasive enough. Therefore, they may refuse to accept and follow the advice. Another barrier that prevents individuals from seeking support is their "uncertainty about the reliability of the support system" (La Gaipa 127). For example, the patient and his family may doubt the credibility of a clinic that offers medical treatment, or recipients may notice that the support provider does not have any related experience in solving similar problems.

   The risks to a person's face further explain a person's hesitation to express his needs and to seek support. Goffman defined *face* as an individual's "public self-image" conveyed through interactions (Goffman 5). Brown and Levinson added to Goffman's notion of face, claiming that individuals all have a desire to maintain their faces. In other words, individuals want others to recognize their competence, appreciate their values, and express concern to them. They also want to be free from "imposition, constraint, or intrusion" caused by others (Brown and Levinson 61- 62; also Hallsten 108). Individuals' assessment of advice as social support could reflect this desire. According to a study by Goldsmith, recipients evaluate advice more positively if the advice supports their faces (*Communicating Social Support* 150). Advice, then, should

communicate liking, concern, appreciation, and acceptance, as well as respect for privacy and recipients' choice of actions (Goldsmith, "The Role of Facework" 32). In contrast, recipients assess advice more negatively if they perceive the advice as a threat to their faces (Goldsmith, *Communicating Social Support* 150). In other words, recipients are less likely to appreciate advice that fails to convey positive feelings towards them, violates their privacy, or imposes certain actions on recipients (Goldsmith, "The Role of Facework" 32).

The desire to protect and maintain face thus creates a tension in which individuals are reluctant to seek and receive support because they worry that such actions may lead to negative impressions of their competence and autonomy (Goldsmith and Parks 107; La Gaipa 125). For instance, an American student may refuse to have an international student tutor at the college writing center proofread her essay because she does not want to admit that a non-native speaker could be a better writer than she. The student may think that the support from the tutor conveys a negative image of her own competence. Other than their concern about face, recipients also hesitate to express support needs because they do not want to trouble the providers with their problems or because they worry that the providers will disclose the information to others (Goldsmith and Parks 107).

The Integration of the Structural and Functional Approaches

The structural approach explains how properties of individuals' social networks such as size, density, and intensity could influence the flow of supportive resources to network members. This approach is useful to identify favorable network properties that allow more supportive resources as well as properties that constrain individuals' access to these resources (Hall and Wellman 26-27 and 32). Rather than relying on "simple measures of social structure" to examine support (Hall and Wellman 37), the functional approach studies the effect of specific types of

social support on individuals' well-being (Cutrona 7; House and Kahn 85). Nevertheless, the

functional approach often examines the support process within dyadic relationships of providers

and recipients, while ignoring the impact of larger social networks in which transactions of

support occur. As a result, this approach only attends to perspectives of support providers and

recipients, while it neglects perspectives of potential providers outside of the dyads (Pierce,

Sarason, and Sarason 184). Although each approach has its strengths and weaknesses, the

structural and functional approach could complement each other. While the functional approach

focuses on a smaller scope of the support process, the structural approach offers a view of social

support in a broader range of interpersonal relationships within social networks, not only the

relationships between a focal person and others, such as the person's friends, but also the

relationships among "friends of those friends" (House and Kahn 91). For example, the structural

approach to social support in a marital relationship looks at both the exchange of support

between spouses and how the couple's relationships with other people, such as extended family

members and professional colleagues, can influence the support that the couple receives in the

future. Therefore, in order to examine the support process more comprehensively, it is important

for researchers to integrate the structural and functional approaches (House and Kahn 104;

Pierce, Sarason, and Sarason 74).

Studying social support from both structural and functional perspectives is crucial

because the structural aspects of social networks influence the supportive functions that the

networks fulfill (House and Kahn 84-85; Walker, MacBride, and Vachon 35-37). Networks with

large membership, high density, high homogeneity, and low dispersion provide members with

more emotional and instrumental support (Israel 67; Walker, MacBride, and Vachon 35-37). In

other words, networks that have a high number of members who know each other well, share

demographic characteristics, and live within a geographically close distance provide favorable conditions for the members to receive more emotional and instrumental support. A network of friends from the same country may provide an international first-year student with more emotional support because these friends greatly understand the culture shocks that the student experiences and empathize with her worries and concerns. Another illustration is that family members who live close to each other could easily provide tangible help to one another, such as babysitting the kids while parents are away for work or taking care of the elders. However, social networks with low intensity and homogeneity allow more informational support because these properties permit network members to learn new and diverse information from others who are less close to them and who do not share similar backgrounds or characteristics (Walker, MacBride, and Vachon 35-37). For instance, at a conference on economic inequality in a developing country, a network of attendees who are representatives of different institutions and specialized in different issues would bring a diversity of perspectives on the problem as well as possible coping strategies for alleviating it. Beyond taking a cohesive approach to analyze both the structure of social networks and the supportive functions that these networks provide, researchers should attend to two other influential factors, namely personal and environmental attributes.

Personal and Environmental Factors that Influence the Support Process

Personal and environmental factors not only can determine whether support is desirable and effective (Albrecht and Goldsmith 274-274; Cohen and Syme 12-13; Goldsmith, *Communicating Social Support* 83-84), but can affect individuals' preference for support-seeking (Taylor, Sherman, Kim, Jarcho, Takagi, and Dunagan 354; Xue, Ooh, and Magiati 415-416). Cutrona, Suhr, and MacFarlane in applying Kelley et al.'s framework of causal conditions in

dyadic interactions (Kelley et al. 52) to the study of social support, argued that personal and environmental factors additionally dictate the "recurrence of supportive or non-supportive interactions" among individuals (Cutrona, Suhr, and MacFarlane 34).

Personal factors include age, gender, marital status, social competence, personality, sociocultural roles, and individuals' ability to cope with stresses or to seek, activate, and sustain social support. These factors influence providers' ability to give support as well as recipients' interpretation and assessment of received support (Cohen and Syme 10; Goldsmith, *Communicating Social Support* 113-114; Goldsmith, "The Role of Facework" 34; Goldsmith and Fitch 456; Pierce, Sarason, and Sarason 187). A student who holds a leadership role in different organizations could mobilize more people to support a political campaign on campus than others might. A company with a strong economic base is more likely to offer financial support, such as loans or donations, than a startup with limited revenue is. Personal factors not only determine the provider's ability and willingness to offer support, but also influence the recipients' demands and evaluation of support. A new entry-level employee who does not know about the operation and working culture of the company well may desire more advice and guidance. Teenagers who experience romantic relationship problems may appreciate advice from their best friends more than advice from their parents.

Other than personal factors, environmental or situational factors also play an important role. These factors include resources, expectations, sociocultural norms, and family or work influences. Environmental or situational factors may either enhance or limit support from potential support providers (Pierce, Sarason, and Sarason 187). A hospital which lacks clinical equipment and qualified doctors could not provide support to patients in the same way as well-equipped hospitals with great doctors could. Furthermore, Taylor et al. argued that sociocultural

norms guide individuals' expectations of and interactions with one another, thus affecting their motivation to seek support (354). According to the authors, collectivist, or interdependent cultures, such as South America, East Asia, and Africa, stress the importance of group harmony and in-group relations. Because individuals in these cultures worry that seeking support may bother others with their own problems and interrupt group harmony, they often hesitate to make explicit requests of support from extended network members and rely on themselves or family members to solve the problems (Taylor et al. 359).

All in all, human social interactions not only provide the means for transaction of social support but also influence individuals' interpretation of received assistance. In order to understand the use of social support in helping individuals cope with stressful life events, researchers should examine structural and functional aspects that determine the availability and effectiveness of social support, as well as personal and situational factors that govern individuals' assessment of support and manner of support-seeking.

Autism Spectrum Disorders: Diagnosis, Intervention, and Parental Stress

Autism Spectrum Disorders (ASD) encompass a range of developmental disorders which were earlier identified as "infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder" (*Diagnostic and Statistical Manual* 50). Diagnostic features of ASD include persistent deficits in social communication ability that hamper a person's engagement in reciprocal interactions, expression of inner thoughts and feelings, and adjustment of behaviors to social contexts. Individuals with ASD have poor nonverbal communication skills displayed in their reduced or abnormal eye contact, absence of facial expressions, and failure to use and understand body language. As a result, these

individuals face a great difficulty in relationship establishment and maintenance (*Diagnostic and Statistical Manual* 50-53).

ASD is also identified with a person's hyperactivity, as well as restricted and repetitive behaviors, interests, and activities such as lining up objects, flipping or spinning coins, and repeating words and phrases of others. Individuals with ASD often insist on routine and resist changes (*Diagnostic and Statistical Manual* 50). This inflexibility contributes to their poor adaptive skills that impede academic achievement and independent living (*Diagnostic and Statistical Manual* 57). According to Paul and Norbury, ASD has the highest variability in diagnostic features compared to other developmental disorders. This characteristic makes it difficult for professionals to identify the causes of ASD and to develop treatment approaches for diagnosed individuals (119).

In the next section, I will explain the process of ASD diagnosis and intervention in the United States and other countries, and then discuss the stress that parents in these countries experience when nurturing a child with autism.

Diagnosis and Intervention in the United States and Other Countries

While symptoms of ASD are consistent among diagnosed individuals across countries, perception of the disability varies from culture to culture. According to Johnson, individuals from different countries may attribute ASD to different causes. Also, the diagnosis and intervention processes are not the same among countries. The clearest distinction is between developed and developing countries and between Western and Eastern cultures (Johnson 124).

While Western developed countries such as the United States, the United Kingdom, Canada, Australia, and European countries attribute ASD to genetic and environmental factors (Harrington, Patrick, Edwards, and Brand 455), developing countries in which individuals have

little awareness of the disability often attribute ASD to supernatural and spiritual causes. For example, in China, many people consider ASD a consequence that diagnosed individuals have to suffer as a result of their sinful acts against ancestors in past existences (Chiang and Hadadian 113). In the Kingdom of Saudi Arabia, ASD also has a negative connotation. Many Arabs believe that because individuals with ASD committed bad deeds in the past that Allah is now challenging them (Alquraini 142).

ASD diagnosis and assessment processes are different among countries. In Western developed countries, ASD diagnosis and assessment involves a comprehensive process implemented by a multidisciplinary team including pediatricians, psychologists, speech-language pathologists, physical therapists, and occupational therapists. These specialists apply different tests to assess the child's medical conditions. They interview parents and other family members of the child and conduct a series of tests such as an IQ test, a test of adaptive functioning, and an autism-specific diagnostic test for the child in order to provide an accurate diagnosis of the disability (Johnson 126; Falkmer, Anderson, Falkmer, and Horlin 337; Williams et al. 341). According to Yu, Lv, Ohta, and Takahashi, Japan is the most similar to the United States and other Western developed countries in terms of the ASD diagnostic process (503). Japan's multidisciplinary assessment model is consistent with the suggestions of the American Academy of Pediatrics. Japan also requires all children at their 18-month check-up to take an autism-specific screening test provided by public health services (Yu, Lv, Ohta, and Takahashi 503).

Nonetheless, other countries including China, India, Brazil, and Turkey have neither a universal diagnostic system nor a standardized protocol for the ASD assessment process. Parents in these countries often take their children to physicians if they notice peculiar symptoms in the children's communicative behaviors, and physicians mostly make assessment based on the

parents' reports (Daley 1327-1329; Paula 1740-1741; Yu et al. 508-509; Uzum). Johnson

explained that diagnosis and assessment services are often unavailable to children with autism in

developing countries due to the expensive costs of ASD screening tools and diagnostic tests.

Practically, the diagnostic tests developed in the United States and other Western countries may

not be culturally relevant to other nations (Johnson 131). For instance, ADOS-2 test asks

participating children to perform the basic steps of a birthday party celebration such as singing

the "Happy Birthday" song, clapping hands, blowing candles, and eating birthday cake.

However, since people from some rural areas in South African countries actually do not

celebrate birthdays, ADOS-2 test is not relevant to children from these areas (Deweerdt S18).

While the absence of eye contact is a key symptom of ASD in the United States, cultures that do

not encourage eye contact among individuals may not recognize the lack of eye contact as a clear

symptom of ASD (Deweerdt S19). A major purpose of ASD diagnosis and assessment is to

suggest suitable intervention approaches for the patients. Nevertheless, as a result of the limited

options for ASD intervention and treatment in developing countries, pediatricians and parents

often feel reluctant to devote their time and energy to the full assessment process. More

seriously, the stigma and negative implications associated with ASD may prevent parents from

seeking diagnosis and assessment for their children (Johnson 131).

      Countries vary not only in ASD diagnostic and assessment practices, but also in

intervention and treatment approaches for diagnosed individuals. Physicians in developed

countries such as the United States, the United Kingdom, Canada, and Australia provide medical

and behavioral treatment for children with ASD. Since there is no medication to cure the

disability, physicians often recommend that children with ASD take drugs that treat behavioral

symptoms such as hyperactivity, aggression, and overexcitement. For behavioral treatment,

Applied Behavioral Strategies (ABA) is the most promising approach with the strongest empirical evidence. Developed countries also have special education programs for children with ASD and enforce policies to include these children in public schools (Johnson 133).

However, research on treatment for children with ASD remains scarce in developing countries; these nations often lack experienced, competent physicians to prescribe drugs and offer treatment services for diagnosed individuals. As a result, parents of children with ASD have to research medications and treatment for their children through the Internet (Johnson 133). Also, special education programs for children with ASD in developing countries, if they exist, are located primarily in big cities and metropolitan areas (Johnson 136).

Parental Stress

Past research in the United States, United Kingdom, and Poland has shown that parents of children with ASD experience higher levels of stress than parents of children with other developmental disabilities (Brobst, Clopton, and Hendrick 47; Bromley, Hare, Davison, and Emerson 409; Phetrasuwan and Miles 161-162; Pisula 266-267; Silva and Schalock 569; Zablotsky, Bradshaw, and Stuart 1388). Parents in these studies worry most about the child's social communication ability and acceptance by others (Phetrasuwan and Miles 161-162; Silva and Schalock 569). Parental stress also stems from issues such as the child's behaviors, cognitive impairments, and constant dependence on assistance (Brobst, Clopton, and Hendrick 46; Pisula 266-267; Sharpley, Bitsika, and Efremidis 24; Silva and Schalock 569), as well as the lack of time for parents to care for themselves (Phetrasuwan and Miles 161-162). Parents reported feeling "stretched beyond their limits," "unable to cope" with the difficulties of raising a child with ASD, "anxious," "depressed," "isolated," and "awful" (Sharpley, Bitsika, and Efremidis 23). Despite the high levels of stress, parents of children with ASD often receive lower levels of

social support than parents of children with other developmental disabilities. Couples who have a child with autism also endure more marital relationship problems than other couples (Brobst, Clopton, and Hendrick 46; Pisula 266-267).

<center>**ASD in Vietnam: Diagnosis, Intervention, and Parental Stress**</center>

Since the late 1990s, the number of diagnosed ASD cases has increased rapidly in Vietnam (Ying et al. 291). Similar to many other developing countries, Vietnam lacks technological equipment and experienced physicians to support children with autism and their families. The limited research on autism in Vietnam and the absence of official statistics on the disability (Brown; Ha et al. 279) also force Vietnamese parents to conduct their own research in the libraries or through the Internet (Motchan 23). In this section, I will discuss the diagnosis and intervention of ASD in Vietnam to show the difficulties suffered by Vietnamese children with autism and their families. Then I will examine the Vietnamese parents' stress from raising a child with autism.

Diagnosis and Intervention

The Vietnamese National Hospital of Pediatrics website identifies three causes of ASD including neurological injuries, genetic factors, and influences from the environment. The early diagnosis criteria for children over twelve months old listed on the website are similar to the criteria in the *Diagnostic and Statistical Manual of Mental Disorders (DSM),* a standard document used to assess symptoms of ASD in the United States and other countries. According to the website, the hospital uses five diagnostic tests: the Denver, the Ages and Stages Questionnaire (ASQ), the Modified Checklist for Autism in Toddlers (M-CHAT 23), DSM-IV, and the Childhood Autism Rating Scale (CARS). ASD intervention programs in Vietnam focus on teaching behavioral, communication, and social skills for diagnosed children (Nguyen). These

approaches overlap with those mentioned on the "ASD Homepage" of the United States' Centers for Disease Control and Prevention website ("Autism Spectrum Disorder").

Although Vietnam shares similarities in ASD diagnosis criteria and intervention approaches with Western developed countries such as the United States, the United Kingdom, Australia, and European nations, only a few certified public and private institutions in Vietnam offer early diagnosis, intervention, and health services for children with ASD (Park, Glidden, and Shin 45; Ha et al. 279). On its official website, the National Hospital of Pediatrics mentions that one-on-one therapy for children with ASD should include five to six 30-minute sessions per day and that the full treatment process should last from at least 12 to 24 months (Nguyen). However, the limited number of public hospitals that offer intervention services for children with ASD provide only short-term programs that last for three weeks and serve only twenty children per program, with each child permitted to attend a maximum of four programs. Just two public universities have both a full-time and a part-time intervention program for young children with ASD, while services for teenagers and young adults scarcely exist (Ha et al. 282-283).

Parental Stress

In addition to the stress that all parents of children with ASD experience, Vietnamese parents who have a child diagnosed with the disability also suffer additional anxieties. These anxieties include the public's negative perceptions of ASD, the limited availability and high cost of diagnosis and intervention services, the low levels of medical expertise of pediatricians in Vietnam, the difficulty of placing their children in regular public or private schools, and the lack of financial support from the Vietnamese government. While taking care of their children with ASD, Vietnamese parents reported feeling "stressed" and "fatigued," and experiencing "insomnia" and "weight loss" (Motchan 28).

Negative public perceptions of ASD in Vietnam stem from two basic misunderstandings of the disability, one rooted in religion and one in a conflation of ASD with schizophrenia. Vietnamese religious belief in rebirth and karma considers disability a form of punishment that an individual endures as a result of his descendants' bad deeds. This belief paints a cruel and discriminatory view of ASD that brings embarrassment to families of the affected person (Ha, Whittaker, Whittaker, and Roger 284; Hunt 214). A Vietnamese mother reported that people in her home village blamed her family for living immorally and believed that her son got ASD as a punishment (Ha et al. 281). Another mother shared that because of the discrimination against people with autism, her parents "cut off contact" with her and "refused to visit" her son who was diagnosed with ASD (qtd. in Motchan 31). Many parents also mentioned that even service providers advised them to have another child because their child with ASD could not "become a person," is "good for nothing" and "for decoration only" (qtd. in Ha et al. 281). However, a study by Motchan showed that not every Vietnamese parent believes the supernatural is a cause of autism (Motchan 41). Rather than feeling ashamed of their child with autism and hiding his disability from extended families and friends, many parents felt comfortable discussing the child's disability and often preferred to do so because they found their families and friends sympathetic and understanding (Motchan 29).

A second source of negative attitudes towards Vietnamese individuals with ASD and their families emanates from the public's conflation of the disability with schizophrenia. Vietnamese respondents in several studies often associated ASD with schizophrenia and used words such as "insane," "mad," "mentally ill," and "potentially dangerous" to describe individuals with ASD (Ha et al. 281 and 284; Ham, Wright, Van, Doan, Broerse 579; Harpham and Tuan 665). Ham et al. argued that this negative perception might occur due to the constant

focus on schizophrenia in Vietnam's mental health programs (579). Whether rooted in the supernatural or inaccurate associations, the social stigmas associated with ASD lead to some parents' refusal to admit the child's disorder and to seek intervention services or developmental programs for the child (Brown; Park, Glidden, and Shin 40).

Because of the limited availability of public institutions that offer diagnosis and intervention services, Vietnamese children with ASD greatly rely on private special education programs. Nonetheless, the emergence of unlicensed private schools for this purpose worries parents. *Thanh Nien News* reporters worked undercover at a special school for children with disabilities in Ho Chi Minh City and revealed evidence of physical abuse committed by service providers, including "grabbing a boy by the hair," "ramming his head into a metal door," "leaving him lying on the floor," and "flogging [the boy] with a coat hanger" (Nhu Lich, Lam Ngoc, and Thanh Tung). Moreover, the expensive cost of private special education programs prevents Vietnamese children with autism from long-term participation and puts extra burdens on the parents (Brown; Ha et al. 283). According to a study in 2014 by Ha et al., the cost of a full-time program ranges from 3,500,000 VND (175 USD) to 7,000,000 VND (350 USD) per child per month, which accounts for 35 to 70 percent of the average monthly income that half of the parents who participated in the study earned. Even if the parents can afford the cost, physicians in these programs may reject their children with severe ASD conditions because the children's slow improvement can adversely affect the reported success rate of the special education centers (Ha et al. 283).

Vietnamese parents face many difficulties not only in seeking diagnosis and treatment for their children with autism, but also in enrolling their children in regular public or private schools. Parents of children with ASD claimed in past studies that they wanted their child to

have more friends other than just her siblings and to engage in activities at regular schools more often (Hartley and Schultz 1642; Siklos and Kerns 930). Nonetheless, Vietnamese school managers give different reasons for excluding children with ASD. They tell parents that the school's academic schedule is too inflexible to add special programs for students with autism, that the school does not have enough teachers to give the children special care and support, or that the school is already full (Ha et al. 281-282). Additionaly, both the teachers' lack of skills in teaching children with disabilities and peer discrimination discourage parents from sending their children with ASD to regular schools. Parents reported their children being "hit," "shoved," "pushed," "bullied," "ignored," and "left out of activities" by classmates in regular schools (qtd. in Ha et al. 282).

The qualifications of pediatricians in Vietnam also concern the parents. Health professionals, physicians, and students in Vietnam learn only theoretical knowledge about ASD without sufficient clinical experience and practice (Brown). Dr. Nguyen Thi Hoang Yen, the Deputy Head of Education and Science, claimed in an interview with *Thanh Nien News* that Vietnamese pediatricians do not fully understand the diagnostic features of ASD and that they lack critical skills in diagnosis. Thus, Vietnamese children with ASD often endure late detection of the disorder at the time they reach higher levels of severity (qtd. in "Number of Children"). Because physicians in Vietnam often do not receive adequate compensation for their efforts, many physicians open private services for additional income (Khuu 6). The need for extra earnings often compels some Vietnamese physicians to "make money off the drugs" (qtd. in Motchan 23), thereby causing patients and their families to lose trust in the physicians (Motchan 23). Vietnamese parents of children with ASD also reported that despite the severity of their child's disability, pediatricians only give general recommendations and advise that the child

should attend normal schools (26). Overall, parents expressed their dissatisfaction with the diagnosis and treatment services in Vietnam, describing these services as "rushed," "inaccurate," "vague," and "confusing" (qtd. in Ha et al. 282).

Another source of stress experienced by Vietnamese parents of children with ASD is the lack of financial support from the government. No legal document in Vietnam recognizes ASD as a type of disability. While Vietnam's Disability Law specifies five groups of disabilities that are eligible for governmental support and welfare payment, ASD does not fit into any of the groups (Ha et al. 282). Therefore, families of children with ASD do not qualify for any benefit that families of children with other disabilities receive from the government. In addition, Park, Glidden, and Shin mentioned that Vietnamese local governmental offices refuse to provide support for families of children with cognitive delays of any kind because they believe that it is the family's responsibility to take care of their children (40). Vietnamese officials seem to see ASD as a "family problem" rather than a life-long developmental disability that calls for support from the government (Ha et al. 284).

Indeed, Vietnamese parents of children with ASD suffer from intense stress and anxiety because of the Vietnamese public's negative perceptions of the disability, the limited availability of diagnosis and assessment for their children, and the expensive cost of private intervention services. The extensive barriers to their children's enrollment in regular schools, the low qualification and reputation of physicians in Vietnam, and the lack of financial support from the Vietnamese government add extra burdens on the parents. Despite the need for social support of Vietnamese parents of children with autism, research on social support in general and social support for these parents in particular remains scarce in Vietnam. In the next section, I will examine prior studies on social support for parents of children with autism in other countries. A

review of these studies may provide useful suggestions for future research on the topic in Vietnam.

Social Support for Parents of Children with ASD:

Research in Countries Other Than Vietnam

In this section, I will examine positive effects of social support on reducing stress and improving health for parents of children with ASD; then I will discuss past scholarship on the parents' self-reported needs for social support.

Social Support as Stress-Coping Assistance

Two studies in the United Kingdom showed that the quantity and quality of social support given to parents of children with autism strongly impacts the parents' levels of distress and psychological well-being. While parents who receive low levels of support have increased distress and decreased psychological well-being (Bromley, Hare, Davison, and Emerson 420), parents who receive more support, especially support which they perceive as helpful, experience lower levels of stress and higher levels of psychological well-being (White and Hastings 187). The correlation between social support and parental stress reflects Thoits' conceptualization of social support as coping assistance (417).

Nevertheless, Bristol and Schopler argued that parents of children with ASD are not only passive receivers of support, but also active agents who employ coping strategies to alleviate their stress. The authors divided the parents' stress-coping strategies into instrumental coping, parental beliefs, and palliative actions. The instrumental coping strategy refers to the parent's attempts either to change the child with autism or the environment that surrounds him. The parents may modify the child's behaviors at home, take the child to intervention services, or enroll the child in a different school (Bristol and Schopler 265). Parental beliefs is a perception-

oriented strategy in which the parents view the stressful event through a positive lens in order to make the event more bearable. For instance, parents may believe that God will protect and give strength to the child with ASD during her adaptation to adult life. Lastly, parents can reduce their stress through palliative actions such as taking stress-relieving medications or seeking alternative sources of enjoyment in new hobbies or interests (Bristol and Schopler 267).

Parents' Self-Reported Needs for Social Support

In order to give useful recommendations for social support to assist parents of children with ASD in overcoming their stress, researchers should attend to the needs for social support requested by these parents (Hartley and Schultz 1637). Results from studies across the United States, the United Kingdom, France, and Canada showed similarities in support needs that parents identified as important yet unmet. According to these studies, parents of children with ASD are in need of instrumental, informational, emotional, and relational support, as well as support for the social development of the child with ASD. While parents often request instrumental and informational support from formal sources such as pediatricians, therapists, speech-language pathologists, and teachers, they have a high expectation for emotional support from informal sources such as family members, friends, and other parents of children with ASD (Bromly et al. 419; DeMyer and Goldberg 237; Derguy, Michel, M'Bailara, Roux, and Bouvard 159-160; Hartley and Schultz 1640-1642; Sharpley, Bitsika, and Efremidis 20; Siklos and Kerns 928-930; Thoits 420; White and Hastings 187).

Instrumental support requested by the parents includes financial assistance to provide the child with therapy and care (Derguy et al. 159-160; DeMyer and Goldberg 237; Siklos and Kerns 930; Bromley et al. 419). Parents of children with ASD in prior research also called for well-trained and experienced professionals who respect the parents and give honest information about

the child's health conditions (Derguy et al. 159-160; DeMyer and Goldberg 237; Hartley and Schutlz 1640; Siklos and Kerns 928; White and Hastings 187). Moreover, the parents expressed their desires for appropriate specialized institutions that promote the child's health development through continuous treatment programs rather than short-term interventions during times of crisis (Hartley and Schultz 1640).

Informational support ranks second in the list of important yet unmet needs of the parents. Parents not only wanted to enhance their knowledge about ASD, but also to improve their parenting skills in order to manage the child's emotional and behavioral functioning at home (Derguy et al. 159-160; DeMyer and Goldberg 237). Additionally, parents requested information with regard to special education programs for their child with ASD, as well as advice from professionals on appropriate services and future education plans for the child (Bromly et al. 419; Hartley and Schultz 1640; Siklos and Kerns 930).

Other than instrumental and informational support, emotional support given by family members, friends, and other parents who share the experience is also valuable. Such support can be as simple as listening to the parents' sharing of thoughts and feelings and agreeing on the parents' decisions on intervention and therapy for the child (Derguy et al. 159-160; DeMyer and Goldberg 237; Hartley and Schultz 1642). White and Hastings claimed that helpful support from these informal sources has the most positive correlation with parents' well-being (187). According to past studies in the United States and Singapore, immediate family is the most common source of emotional support reported by parents of children with autism (Sharpley, Bitsika, and Efremidis 20; Xue, Ooh, and Magiati 412). In research by Xue, Ooh, and Magiati, parents listed spending time with family, receiving help from family members in nurturing the child with ASD, and sharing feelings with spouses among the most helpful ways to cope with

stress (412-413). Parents also reported that if they noticed family members who provided support clearly understood their child's disability and needs, the parents would feel less stressful and depressed; they even became more confident in their ability to support the child with ASD. Thus, researchers suggested including other family members of the child with ASD in informational and training workshops and providing them with essential knowledge and skills to assist the parents (Sharpley, Bitsika, and Efremidis 25-26).

Another informal source of functional support that parents of children with ASD consider effective in coping with stress is other parents of children with autism (Thoits 420; Xue, Ooh, and Magiati 412). Their shared experiences of raising a child with ASD allow these parents to understand the associated distress better and to empathize with one another. Parents also find the advice from other parents more applicable and acceptable than that which comes from family members (Thoits 420). As a result, many parents of children with ASD come together and form social support groups in which they can expand their support networks and exchange informational, psychological, and emotional support with one another. Several studies across the United States, Ireland, and Greece have shown the positive effects of social support groups on parents of children with ASD. Through their participation in these support groups, parents form meaningful connections with other parents who share their feelings and experiences; they also receive helpful advice as well as updated information about developments in treatments for the child with ASD (Brobst, Clopton, and Hendrick 47; Papageorgiou and Kalyva 657; Reinke and Solheim 2368). Cantwell, Muldoon, and Gallagher suggested that emotional support given by parental support groups may also alleviate the negative consequences of stigma, which often stem from having a child with disability, on the parents' psychological well-being (Cantwell, Muldoon, and Gallagher 955-956). One way through which parents access social support groups

is the internet. According to Reinke and Solheim, parents find online support groups offer a "reciprocal mutually supportive environment" (2368). The findings showed that parents share their thoughts and feelings with other parents in online support groups more often than with their family members (2368-2369).

However, Clifford and Minnes argued that parents of children with autism actually have conflicting perspectives on the effectiveness of social support groups. According to their study on Canadian parents of children with ASD, many parents who were members of support groups reported learning more "adaptive coping strategies." In contrast, some felt disappointed with the benefits that the support groups provided and finally left the groups. The latter set of parents explained that the support groups in which they participated put great emphasis on sharing information while neglecting emotional assistance for parents (Clifford and Minnes 183). The study also showed that parents who had not participated in any support group could hardly attend the group meetings because of difficulties relating to meeting location and time (Clifford and Minnes 183). These results indicate that social support groups may not benefit all parents of children with ASD. Thus, rather than utilizing support groups as a "one-size-fits-all" strategy, researchers should examine other approaches that put greater emphasis on parents' individual needs (Clifford and Minnes 185-186)

Parents of children with ASD also have a great desire for relational support to maintain satisfactory relationships with their child, spouse, and other family members (Derguy et al. 159-160). A study by Brobst, Clopton, and Hendrick showed that when children with autism exhibit more behavioral problems, the mothers often receive less support from their husbands. Therefore, problem-focused and emotion-focused coping approaches for parents of children with ASD should attend to enhancing spousal communication and strengthening marital relationships

so that the parents can provide better support for one another (Brobst, Clopton, and Hendrick 47; Hartley and Schultz 1646).

Hartley and Schultz argued in their study that while fathers and mothers of children with ASD shared similar demands for social support, the mothers often reported a higher number of needs and unmet needs than fathers did. This finding may imply that mothers are more involved in childcare and the intervention process (Hartley and Schultz 1645). While the mothers' unmet needs focused on expertise of professionals, expressions of compassion and understanding from family members and friends, and private time with their spouses, the fathers' unmet needs focused on self-care and respite such as getting enough sleep, going out for dinner, or having vacations (Hartley and Schultz 1642-1646). The study also discussed several factors that influence parental needs for social support. Parents whose child with ASD was younger or had more intense restricted behaviors had to make greater efforts to take care of the child. Therefore, these parents requested more social support to assist them in caring for the child to relieve parental stress. In addition, parents who had lower levels of education often had more unmet support needs. Hartley and Schultz explained that the complexities of healthcare and educational systems for children with ASD may prevent parents with lower education levels from approaching this formal type of social support (Hartley and Schultz 1646).

Overall, social support plays a crucial role in reducing parents' uncertainty about the stressful experience of raising a child with autism. For instance, informational support eliminates the ambiguity of the stressful event because it enables parents to interpret the event and be aware of suitable coping actions. Receiving support from social network contacts reduces the parents' uncertainty about the intimacy and stability of their relationships with support providers in their network, as well as the availability of future support from those providers. Parents'

acknowledgement of available support from both formal and informal sources also reduces the parents' negative feelings while increasing their confidence in the ability to cope with stress and to provide better care for their children.

In order to accommodate the special needs of parents of children with ASD, social support providers should attend to functional support requested by the parents such as instrumental, informational, emotional, and relational support. Nonetheless, support providers should not neglect important structural aspects of parents' desired support including the sources of support and the quantitative and qualitative properties of the support networks. Parents of children with ASD not only seek support from formal sources such as pediatricians, psychologists, therapists, and special education teachers, but also from informal sources such as spouses, family members, and other parents who have children with autism. The parents' self-reported needs for social support also imply certain properties of support networks that the parents wish to have. For instance, their desire to increase contact with formal support providers such as physicians and informal support providers such as other parents of children with ASD reflects the parents' need to extend the size and density of their support networks. The homogeneity in terms of parenting experiences among online support group members also explains why parents find support from other parents of children with ASD helpful. Additionally, the parents' need to enhance marital relationships and spousal communication indicates their wish for the durability and reciprocity of supportive relations with spouses.

Conclusion

Social support is a promising approach to assist parents of children with ASD in reducing uncertainty about the disability and treatment for the child with autism, overcoming stress, and improving well-being. However, these parents' specific needs for social support vary with both

healthcare systems across countries and social norms and expectations across cultures. Other factors such as the severity of the child's disability, parents' levels of involvement in childcare, and the availability of support from social network members also influence the parents' needs for social support. This past scholarship provides a useful context for my study on the social support needs of Vietnamese parents of children with ASD. In the upcoming chapter, I will explain the method used in my research on the needs for social support of Vietnamese parents who have a child with autism.

CHAPTER III: METHOD

After providing a foundational understanding of social support and Autism Spectrum

Disorders (ASD) through a review of past scholarship, I now turn to my own study on the needs

for social support among parents of children with ASD in urban areas within Vietnam. The study

used a qualitative method of ethnographic interviews to gather information relating to the

specific types and sources of support that the parents desired and the reasons behind their

requests. These interviews offered detailed description and explanation of the parents' needs for

social support through in-depth conversations between the researcher and ten selected

participants. In this chapter, I will present my justification for using ethnographic interviews, the

explanation for my choice of participants, a brief description of each participant, an overview of

interview questions, and a discussion of specific methodological steps to conduct the study.

Justification of Method

Ethnographic interviews are an ideal method for this study because of the various

advantages that this method offers. First, ethnographic interviews allow researchers to examine

communication phenomena in context (Frey, Botan, Friedman, and Kreps 285-286; Yuan 144).

Quantitative methods such as questionnaires and survey interviews can help researchers identify

and categorize the needs for social support of Vietnamese parents who have a child with autism.

Nonetheless, in questionnaires and survey interviews, participants can only select answers from

fixed options without being able to defend or further explain their responses (DeWalt and

DeWalt 138). On the contrary, the open-ended questions in ethnographic interviews give

participants more freedom to recall and reflect on experiences in their own words and with

specific illustrations (Frey, Botan, Friedman, and Kreps 285-286; Yuan 144). Thus, using

ethnographic interviews in this study not only informed the researcher of the parents' needs for

social support, but also provided in-depth explanations of personal and situational factors that led

to those needs. Furthermore, participants in ethnographic interviews have more chances to express their thoughts and feelings and may provide answers that researchers do not expect (Frey et al. 290; Lindlof and Taylor 173). Ethnographic interviewers can also clarify and elaborate particular points in the participants' answers throughout the interview process (Yuan 144). Indeed, ethnographic interviews allowed me to gain deeper insights into the parents' lived experience when raising a child with autism.

Participants

Participants of this study included ten Vietnamese parents who lived in urban areas within Vietnam. Compared to suburban and rural citizens, most of the Vietnamese urban citizens are more educated and have higher income. Also, the Vietnamese parents of children with ASD in urban areas have greater access to supportive resources such as advanced healthcare technology and services. The needs for social support of these parents may thereby imply higher needs for social support of parents in less developed locations in Vietnam.

All of the participants were members of local autism clubs, the parent-run support groups which coordinated informational and training workshops for parents and social events for their children with ASD. Most of the funding for these groups came from members' donations. The local autism clubs sometimes invited both ASD professionals in Vietnam and from abroad to speak at the workshops. Some groups also had connections with autism clubs in other countries and often sent parents to attend conferences on autism organized by those clubs. Of the ten parents participated in my study, three were males and the rest were females. Selecting participants from the two gender groups allowed me to identify the differences in support needs between Vietnamese fathers and mothers, as mediated by gender roles in Vietnamese culture. Two participants in the study were parents of the same child. Interviewing the couple informed me of the needs for social support relating to marital relationship problems that Vietnamese

parents might face when raising a child with autism. To diversify participants based on factors that influence the parents' needs for social support as suggested in prior studies, I chose parents whose children with autism were different in terms of age, gender, and levels of ASD severity. I also interviewed both parents who enrolled their children with ASD in regular schools and those who did not. The following section will provide a brief description of each participant.

"An" was an employee at a bank. She had two sons and the youngest one was diagnosed with autism. He studied at a private kindergarten and attended one-on-one intervention sessions for two hours every day after school.

"Ba" worked for a telecommunications company. He lived with his wife and their two children. His son with ASD was his second child, who went to a public primary school after several years attending different intervention programs.

"Kim" was an office worker. She lived with her husband and son, who was diagnosed with ASD. She sent her son to a private kindergarten and hired a private special education teacher to support him in class.

"Lan," who was a teacher, lived with her husband and their three children. Her daughter with ASD was about twenty years old and was the oldest child in the family. Lan's daughter no longer went to school and only stayed at home with the parents.

"Linh" was an accountant. She lived with her husband and their nine-year-old child who was diagnosed with ASD. The child went to a public primary school with a private assistant teacher.

"Ly" was an office worker whose husband passed away couple years ago. Her second son was diagnosed with ASD. At his age of ten, he was still unable to speak. Ly sent him to a specialized class of ten children with autism.

"Mai" resigned from work when her son was diagnosed. She homeschooled her son

with ASD, teaching him essential life skills to take care of themselves in daily activities.

"Sang," Mai's husband, worked for a transportation company. Sang and Mai had two children: a daughter and a son. Their son with ASD was the second child, who was 15 years old but still had no language skills and did not go to any schools.

"Nam" was a broadcast journalist. He lived with his wife and their three children. His oldest daughter, who was 12 years old, was among the most severe cases of ASD in the study. She did not attend regular schools, but spent five days every week at a private intervention center.

"Tam," who was a teacher, lived in a family of five people: Tam, her husband, and their three children. Her six-year-old child was diagnosed with ASD. The child went to a private primary school and attended an intervention program once or twice a week.

Overview of Interview Questions

Each interview started with general background questions such as: "How old are you?"; "How many members are there in your family?"; and "What is your job?" The next questions aimed to understand the child's current health condition, the parents' previous knowledge about ASD before diagnosis, and the types of intervention or therapy that their child had received. I also asked the parents to describe their experience of raising a child with autism. The questions included: "How does having a child with ASD affect you and your family?" and "Are there any issues that have been particularly challenging? If so, how? If not, why not?" Because many people in Vietnam thought of social support as social welfare, I explained to the parents how my study used the term differently before asking them about social support. After the parents understood what I meant by social support, I continued the interviews with specific questions about functional support including informational, emotional, instrumental, esteem, and network support. For each type of functional support, I asked the parents a similar set of questions. First, I

asked them if they had ever received that type of support while raising their child with autism.

Then, I asked them to specify the support that they received, to list the people who provided

them the support, and to describe their relationships with the support providers. Moreover, I

included questions such as: "How would you evaluate the support that they give you?" and "Is

there any way that you would suggest these individuals improve the support they provide?"

Lastly, I asked the parents which support was the most important and which was the least

important to them, as well as any additional support that they wished to receive. The full list of

questions can be found in Appendix A. Although I had prepared all the questions before

conducting the interviews, the unique responses of each participant led to slight variations in my

follow-up questions and direction of the interviews.

Methodological Steps

Before recruiting participants for the interviews, I submitted the protocol of my research

to The College of Wooster Institutional Review Board. The protocol included a description of

my study and the method that I proposed to conduct it, a list of interview questions, the

recruitment scripts, and the participant consent form. After the Chair of the Human Subjects

Research Committee approved my protocol, I implemented my study through five major steps:

recruiting participants, conducting ethnographic interviews, transcribing the interviews,

translating the scripts from Vietnamese into English, and analyzing the collected information.

To find participants for my study, I went to Vietnam over the summer and contacted the

local autism clubs in urban areas through emails. Then I scheduled face-to-face meetings with a

representative of each club and ask for suggestions of parents who might want to participate in

my study. After contacting the parents, the representatives gave me phone numbers of parents

who were interested in the study. I called each parent to explain the purpose of my research and

to invite the parent for an individual interview. A day before the interviews, I sent each parent

copies of the interview questions and the participant consent form through emails (See Appendix B for recruitment scripts.)

After having ten parents who met my criteria for participation, I let each parent choose the time and place for our interview so that the parent felt most comfortable during our conversations. The interviews took place at either the parents' houses, individual offices, or quiet coffee shops. Before each interview, I gave the parents two copies of the consent form, each copy included both the Vietnamese and English versions. The interviews did not start until the parents signed the both the consent form to confirm their voluntary participation and commitment. The parents then kept one copy of the consent form and gave me the other copy. (The parents' consent forms can be found in Appendix C.) I completed all interviews in four weeks. Each interview was about 30-45 minutes in length; however, the duration of some was either shorter or longer depending on each participant's response. I used a password-protected smartphone to audio-record the interviews and to store the recordings.

Once I returned to Wooster, I started transcribing the interviews. I coded identifiable information of participants such as names and occupations and stored the interview transcripts in a password-protected laptop. Since I conducted the ethnographic interviews in Vietnamese, I then translated the interview transcripts into English and used them for my analysis. I saved the English transcripts in the same password-protected laptop.

The last step was to conduct my analysis of the interviews. According to Frey et al., ethnographic interviewers should begin analyzing their collected messages as soon as possible to recognize key themes, ideas, and patterns emerging or re-occurring across the interviews (290-291). In my analysis, I looked for the parents' description of their difficulties in raising a child with ASD, evaluation of social support that they had received, and requests for additional social support. Another goal was to collect representative examples from each parent's story.

When the study was complete, I deleted the audio recordings and transcriptions off the smartphone and laptop. I kept the printed Vietnamese and English transcripts used for my analysis private and stored them in a locked suitcase in my single room. After I finished my analysis, I destroyed the transcripts with a paper shredder.

Conclusion

In sum, Chapter III has justified the usefulness of ethnographic interviews for my study, explained my selection of participants, and discussed specific steps taken to conduct the interviews. Ethnographic interviews are beneficial to obtain insightful knowledge of the respondents' lived experience and communication behaviors through intensive, informal, and conversational dialogues. After recruiting participants based on specific criteria, I conducted ethnographic interviews with the participants individually in their chosen settings. Then, I transcribed the interviews, translated the interview transcripts, and analyzed the interviews to detect major patterns that arose across the participants' responses. The goal was to gain a thorough understanding of the functional and structural characteristics of social support that Vietnamese parents who have a child with autism desire. Accomplishment of this goal required a careful examination of the parents' self-reported stress, assessment of available support, and requests for further assistance. The following chapter will present a detailed analysis of the information collected from the interviews.

CHAPTER IV: ANALYSIS

Social support is a promising approach to eliminate the uncertainty and stress experienced by parents of children with ASD. In order to fulfill parents' needs for social support, support providers should understand parental stress of raising a child with autism, evaluate the effectiveness of support that the parents receive, and listen to the parents' request for additional assistance. This chapter will first provide an overview of the participants' children, then examine the challenges of raising a child with ASD in Vietnam from the parents' points of view. Chapter IV will also discuss the social support that the parents received and their evaluation of it, as well as the additional support that the parents desired.

Overview of the Participants' Children with Autism Spectrum Disorders (ASD)

Nine children with ASD whose parents participated in the study were diverse in age, gender, and birth order. Three children were within four to six years old; three were nine; three were teenagers; and one was twenty years of age. Two of the children were girls; five of them were boys; and the gender of two other children was unknown because their parents did not mention it in the interviews. All of the five boys were the youngest child in a family of two children, and both of the two girls were the oldest child in a family of three children. Of the two children with unknown gender, one was the only child and the other was the middle child. Backgrounds of the children also varied in terms of their diagnosis, intervention, education, and current health condition. The next section will discuss these differences in details.

Diagnosis

Most of the children were diagnosed with ASD at two years old (An, Ba, Kim, Lan, Linh, Ly, Mai, Sang, Tam). Before diagnosis, their parents knew nothing about autism. As the parents noticed their children's delayed speech and language development and increased degrees of

psychological and behavioral disorders, they took their children to the hospitals and were shocked when the doctors concluded that their children were diagnosed with ASD (An, Kim, Linh, Ly, Mai, Sang, Tam). Despite official diagnosis, An's and Linh's family initially neither accepted the test result nor supported the mothers in seeking treatment for their children due to the expensive cost (An, Linh). Different from other children in the study, Lan's daughter, who was about twenty years old, had her diagnosis much later at five (Lan). Lan's daughter was the oldest child with ASD in the study, and by the time she expressed symptoms of autism, information about ASD in Vietnam was nearly nonexistent. Only when the child reached age five was she officially diagnosed with ASD (Lan).

Intervention and Education

The parents in this study selected different intervention and education approaches for their children with autism. Ba and Tam let their children attend regular schools in the morning and send them to intervention centers in the afternoon (Ba, Tam). The parents saw regular classroom an "inclusive environment" where their children with autism could improve social communication skills through interactions with typically developing peers (Ba, Tam). Different from Ba and Tam, Linh stopped sending her child to intervention programs and only let the child learn at a regular public school (Linh). She explained that most intervention programs were for younger children, so they were no longer suitable for teenagers like her child. An and Kim also included their children in both regular and special education programs. Nevertheless, instead of taking their children to intervention centers, the two mothers invited special education teachers to provide one-on-one intervention for their children at home (An, Kim). The parents of children with severe autism, however, found it impossible to enroll their children in regular classrooms because the children had no language skills and suffered from serious cognitive disorders (Ly,

Mai, Nam, Sang). As a result, they either taught their children at home (Lan, Mai, Sang) or only sent their children to special education centers (Ly, Nam). Lan's daughter used to study at a private primary school for seven years and attended a special education program for a few years after that. Finally, Lan had to keep her daughter at home because she could not find any programs for young adults with ASD like her daughter (Lan). Mai and Sang created a special classroom and hired special education teachers to teach their son and five other children with autism at home. The couple did not find intervention programs at private centers helpful because they saw no progress in their son despite years of intervention (Mai, Sang).

Health Condition

Most parents evaluated that their children with ASD were healthy. After intervention, Mai's son ate and slept better and his health greatly improved (Mai). In contrast, Lan and Ly reported that their children suffered from digestive disorders and sleep disturbance (Lan, Ly); while Nam, whose daughter was among the most severe cases of ASD in the study, expressed his concern about his daughter's mental health as she became an adolescent: "She has a lot more negative behaviors and attitudes," Nam said. "She is more irritable, cannot control her behaviors, and is easily roused" (Nam). The divergence of the children's condition later influenced the parents' needs for intervention and education programs that would address their children's unique needs.

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The Stressful Experience of Raising a Child with ASD

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Similar to other parents of children with ASD, the Vietnamese parents in this study experienced high levels of anxiety and stress arising from their uncertainty about their children's development, health improvement, and inclusion into education and other social settings.

Stress Related to Special Education

Not only did the parents feel uncertain about the credibility and effectiveness of

intervention programs, but they also endured great financial pressures to cover the cost of treatment for their children and experienced constant worry about the children's safety at intervention centers. As previously discussed in Chapter II, Vietnam lacks public health institutions that offer long-term intervention programs for children with ASD (Ha, Vu Song, Andrea Whittaker, Maxine Whittaker, and Sylvia Rodger 279; Nguyen; Park, Glidden, and Shin 45). Nam, who had spent more than ten years raising his daughter with autism, confirmed that only one public hospital in his city had special education programs for individuals with ASD, with each program lasted for a couple months and accepted a limited number of participants (Nam). As a result, most parents had to seek treatment for their children at private centers. While some children showed progress after attending intervention programs at private centers (Ba, Kim), others either made slow improvement or no improvement at all (An, Mai, Kim). An's son even developed more challenging behaviors after studying alongside other children with ASD in the programs (An).

Moreover, Kim reported that many private centers only provided one type of treatment, such as occupational therapy or speech-language pathology. The absence of a comprehensive center that offered a full range of treatments forced Kim to take her son to different centers, consuming a great amount of time, money, and efforts (Kim). "I cannot allocate my time to be here in the morning and be there in the afternoon," Kim said, "How about our jobs? Only if we resign from our jobs that we can take the children to all of those centers" (Kim). The large number of private special education centers that focused on early intervention also excluded teenagers and young adults with ASD (Linh, Mai, Sang).

In addition, the expensive costs of intervention at private centers exerted great financial pressures on the parents (Ba, Mai, Linh, Ly). Ba lamented:

Ever since my son first started the program back in 2008, the monthly fee was already

four million dong per child [about $230]; and, to be honest, my salary then was only a bit

higher than that. Later on, it gets more and more expensive, up to five to seven million

dong [$250 to $350] and some centers become outright profit-oriented businesses. (Ba)

Mai reported the same monthly service costs, which could increase to ten million dong ($500) if

a child attended in one-on-one intervention (Mai). Due to rising costs, Ly could no longer afford

to have her son study at private intervention centers; instead, her son went to a special education

school that focused on other types of disability (Ly). "The teachers in this school do not

specialize in autism," Ly described. "They only started to learn about it [autism] after the class

was introduced." Rather than receiving any intervention for their disability, her son and nine

other children with ASD only learned basic skills such as "sweeping the floor," "washing their

faces," or "feeding themselves" (Ly). The parents' reports of financial burdens caused by

expensive intervention services overlapped with the findings from past studies (Brown; Ha et al.

283).

The parents also felt skeptical about the credibility of private intervention centers, which

operated independent of supervision of government or any health organization (Lan, Mai). Lan

said that, "Intervention services for individuals with autism in Vietnam are a mess …. and that

greatly affects the parents." She further explained, "If the parents fail to collect enough

information and to process it properly, they risk wasting their money on poor quality services"

(Lan). Different from the findings from past research in Chapter II, the parents did not report any

physical abuse committed by teachers at private intervention centers (Nhu Lich, Lam Ngoc, and

Thanh Tung). Nonetheless, due to the large number of private institutions and the absence of a

reliable governing body, the parents felt uncertain about the credibility and effectiveness of

intervention services offered by those institutions (Lan).

Safety issue in special education schools was another problem that worried the parents. Mai was shocked when she knew that her son was hit by a car in front of the school gate, but the school guard simply ignored the child (Mai). "I couldn't stop worrying about his safety when he was at school." Mai explained, "The school gate always stood wide-open and accident was bound to happen. It wasn't safe at all" (Mai). Thus, she decided to accompany her son in class because she feared that the teachers could not look after all of those "hyperactive" children (Mai). Eventually, in order to ensure her son's safety, Mai kept the child home and opened a small class to teach him and six other children with autism (Mai).

Stress Related to Inclusive Education

In addition to the children's special education, their inclusion in regular classrooms also worried the parents. While the parents recognized the benefits of inclusive education to their children's future adjustment to adult life, some were not able to follow the approach due to the severity of their children's disability (Ly, Mai, Nam). For ten years since Nam's daughter was diagnosed, she had been fully dependent on her parents' assistance and care: "She can't speak, and she can't do anything by herself." Nam described, "Even in the smallest activities such as eating and putting on clothes, or please excuse my language, urinating. Everything is impossible for her to do by herself" (Nam). Because of her serious health condition, Nam's daughter could not study at any regular schools. Adolescence was another factor that kept the parents away from seeking inclusive education for their children. When Lan noticed that her daughter was making progress after studying at an intervention center, she sent her daughter to a private primary school. However, as her daughter was getting to secondary school, Lan no longer found regular classrooms a good choice for her daughter. With the onset of adolescence, her daughter reverted

to many challenging behaviors, so Lan worried that her daughter would get teased by peers, and chose, instead, to send her daughter back to special education school (Lan).

Nonetheless, the children who went to regular schools faced many difficulties in following the classroom rules and interacting with peers. Ba's son exemplified a "complete lack of order" when studying in class (Ba). "He drew random things all over the notebook and wrote on this page a letter, that page another letter." Ba laughed, "Can you imagine that in the middle of the class period, he ran to the flagstaff and urinated? They are typical behaviors of the children with autism that we couldn't control" (Ba). The children's social interactions with peers in regular classrooms also worried the parents. In Chapter II, researchers stated that parents of children with ASD wanted their children to have more friends and to engage in activities at regular schools more often (Hartley and Schultz 1642; Siklos and Kerns 930). While Ly and Tam had a similar desire, they observed that their children always chose to play alone, and that they only played with peers if the teachers required them to participate in group activities (Ly, Tam). Ba's son could not join other students in games and activities during recess because he could not understand the rules of the games (Ba). The children's poor language skills also prevented them from engaging in long and in-depth conversations with normally developing children (Kim, Linh, Tam). Linh shared that her child could only talk to other kids in three to five sentences. It grieved the mother to think that other children would not befriend with her child because of the child's inability to develop meaningful interactions with them (Linh).

The lack of support from faculty at regular schools added to the parents' stress. Lan told me how the "disagreeable attitude of the teachers and the school" forced her to move her daughter to two to three different schools in search of a more welcoming and supportive institution (Lan). Lan recalled: "I couldn't count how many times I had cried my eyes out

because of things like suddenly in a beautiful day, I would receive a phone call asking me to

come and take my child home." Lan continued, "Where my child would go to study? They didn't

care. They just didn't want to have her anymore" (Lan). The regular schools refused to admit

Lan's daughter because they worried that the child's poor academic performance might impact

their overall achievements and rankings negatively (Lan). When asked about the support from

teachers at regular schools, Ba stressed that some teachers expressed their willingness to assist

the parents in helping the child while others did not. Without asking for permission from Ba and

his wife, his son's second grade teacher told other parents in a parent-teacher conference that

Ba's son had autism (Ba). Publicizing the child's disability, the teacher not only hurt the parents'

feelings (Ba), but might also generate greater fear to the parents about how peers would treat

their son.

Stress Related to Public Perception

The pressures caused by the public's poor awareness of autism and the lack of sympathy

for individuals with ASD added extra burdens on the parents. Ly said that her extended family

members and neighbors did not understand the reasons behind her son's behaviors and often

blamed her for not knowing how to teach the child (Ly). Mai recounted how local police officers

were so "irresponsible" and "emotionless" that they neither helped her son find home nor tried to

contact Mai and her husband when her son went lost (Mai). In Chapter II, Motchan reported that

family members, such as grandparents, even rejected children with ASD because of their

discrimination against individuals with ASD (31). Prior research also showed that the public's

negative perception of autism in Vietnam stems from their conflation of ASD with schizophrenia

and their misunderstanding that autism is a punishment for the family's bad deeds (Ha et al, 284;

Hunt 214). In contrast, none of the parents in my study endured family rejection of their child.

Neither did they report that the public associated ASD with schizophrenia or attributed ASD to supernatural causes. It might be because that all of the parents whom I interviewed lived in urban areas where most people were highly educated.

Mai's husband, Sang, believed that people ignored children with autism because they did not realize that these children need help:

> If you do not interact with them in long and in-depth conversations, you could hardly know that they have autism. If they sit still, they look like other normal kids who don't need any special support …. Many kids look pretty and well-behaved. Like kids from affluent families, they dress nicely and look beautiful. But some kids do have difficulties in eating, sleeping, and social interactions, and those difficulties are only revealed in specific circumstances. (Sang)

Since ASD was not easily recognizable, people often found the unusual behaviors of a child with ASD –such as taking away other child's food or going into someone's house—as intolerable (Mai, Sang). That explained Mai's concern when her son went lost. Mai worried that if her son went into someone's house, "people might think he was a thief and would hit him" (Mai). As her son could not speak, it would be impossible for him to explain anything (Mai). The lack of understanding from other people made the parents feel uneasy about their children's future when the parents would no longer be there to protect and care for their children (Linh).

The negative depiction of ASD in media also reflected the public's ignorance and insensitivity towards individuals with autism. In Vietnam, people often use the word "autism" to describe a person who avoids social interactions and isolates himself from social groups. Sang shared that: "In many films, plays, and game shows on TV, people usually use the word 'autism' or 'autistic' to tease and embarrass someone like asking 'are you autistic?' He added, "Those

kinds of joke are hurting the families and their children with autism. If they [members of the public] had more knowledge about autism, situation like that would never happen" (Sang). Sang mentioned a popular reality show on a national television channel that described autism with negative connotations. However, representatives of the channel broadcasting that TV show did not hold any responsibility for their action. They considered it an unexpected accident and explained to the parents that "the show was just for entertainment" and that "they did not mean to offend anyone" (Sang). Even official television network censored by the government still undervalued the necessity of changing the Vietnamese public's perception of autism.

The stress endured by parents of children with autism led to several consequences, one of which was familial conflicts (Lan, Linh). Linh shared that: "Conflict does not happen frequently in my family, but sometimes it does." She recalled, "Sometimes, my husband felt really downhearted, he went out to drink, and got drunk, and when he came home, we did quarrel with each other" (Linh). While past research suggested that couples who have a child with autism endure more marital relationship problems than other couples (Brobst, Clopton, and Hendrick 46; Pisula 266-267), only two parents in my study reported having conflicts with spouses, and both of them stated that those conflicts did not happen on a regular basis (Lan, Linh).

The stressful experience of raising a child with autism also made Linh and her husband fear to have another child because they heard that "if the first child with autism is a boy, there is a 50 percent chance that the second child will have autism" (Linh). For Sang, he chose to "accept the fate" and had no expectation for support from people other than his family and other parents in the autism club (Sang). Sang explained, "Life in Vietnam, as you may know, everything is very limited." He added, "To have enough money to sustain life is already too difficult for many families" (Sang). As people were busy worrying about their own lives, they became emotionless

about the lives of others. Although Sang felt sad about it, he could not do anything but accept the reality (Sang).

Despite their stressful experience of raising a child with autism, the parents in this study did receive social support from multiple sources such as professionals, family members, and other parents in local autism clubs. The following section will examine the support that the parents received and how the parents evaluated the adequacy of such support.

The Social Support Parents Receive and Their Evaluation of It

As noted in Chapter II, the functional approach divides social support into informational, instrumental, emotional, esteem, and network support (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). Nonetheless, the parents in this study did not separate network support from other support types. Instead, they saw network support as a foundation for other functional support to arise. Through their visits to health centers and participation in local autism clubs, in online forums, and in social networking sites, the parents forged connections with other parents of children with autism, physicians, therapists, and special education teachers. These people then became the parents' main providers of other functional support including informational, instrumental, emotional, and esteem support (An, Ba, Kim, Lan, Linh, Mai, Nam, Sang, Tam).

Informational Support

As mentioned in Chapter II, informational support refers to needed information, instruction, and advice for individuals to make sense of stressful events and to be aware of suitable coping solutions (Cutrona 7; Cutrona, Suhr, and MacFarland 31; Goldsmith, *Communicating Social Support* 13). The parents in this study identified professionals, the Internet, and other parents of children with ASD as three main sources of informational support. While some parents specified that the professionals included special education teachers (An,

Lan, Tam), physicians (An, Nam, Sang), psychologists (An, Nam, Sang), occupational therapists (Kim), and speech-language pathologists (An, Kim); the rest used a general term, "specialists," to describe the support providers (Ba, Kim, Linh, Ly). These professionals not only informed the parents of ASD symptoms, but also suggested treatment and intervention approaches for the children with autism (Ba, Kim, Lan, Sang, Tam). Most of the parents formed their first connections with the professionals when they took their children to public hospitals (An, Ly, Nam) and private intervention centers (Ba, Lan, Mai, Sang, Tam). Others attended informational workshops of the autism clubs in which invited professionals gave lectures on ASD (An, Kim, Nam, Sang, Tam). Kim also took independent courses taught by ASD specialists and continued to receive support from those specialists even after these courses ended. "I finished a course taught by a speech-language pathologist," Kim told me. "But later on, whenever I needed advice or assessment of my child, I always received support from her [the pathologist]" (Kim). For An and Tam, another source of information came from their children's private special education teachers (An, Tam).

However, not every parent found the informational support from professionals helpful. Nam shared that professionals in Vietnam could not satisfactorily answer some of his concerns about his daughter's condition. "They don't have thorough information about this issue [autism]," he explained. "The psychologists, for example, don't have much understanding about autism, and they specialize in other psychological disorders" (Nam). The lack of official certification in autism therapy likewise caused Sang to question the qualification of the so-called specialists: "Vietnam has almost no specialist [in autism]. Even if we have any, there is no system to assess their qualifications." Sang continued, "People call themselves specialists, and the press hails them as experts in the field. But even specialists recognized by the public have

almost no significant success [in ASD treatment]. Not only did Sang stress the limited number of professionals specialized in ASD in Vietnam, but he also expressed his lack of confidence in their qualifications.

Seeking informational support from professionals in other countries was no easy task either. While the connection to international support groups allowed the Vietnamese autism clubs to invite professionals from abroad to the informational workshops (Lan, Ly, Mai, Sang), these workshops did not take place regularly due both to the high travel cost and to the club's budget constraints (Lan, Ly). Mai wanted to follow up with the invited professionals after the workshops to ask for private consultations, but the expense of such services and Mai's inability to speak another language prevented her from receiving the desired support (Mai). Sang added that the professionals invited by the autism club in which he participated, both Vietnamese and international, often gave theoretical explanations of intervention approaches rather than specific instructions of practical, evidence-based methods that could lead to significant improvement in the children (Sang).

The lack of qualified professionals in Vietnam and the limited access to professionals from abroad forced the parents to rely on a second source, the Internet, for informational support (An, Ba, Kim, Linh, Ly, Mai, Nam, Tam). The parents' dependence on online sources resonated with the findings from past scholarship. Chapter II mentioned that the scarcity of research on ASD in developing countries and the lack of experienced physicians compelled parents to search for treatment through the Internet (Johnson 133). Akin to the support given by professionals, informational support on the Internet included content about ASD symptoms, treatment approaches, and intervention strategies (An, Ba, Kim, Linh, Ly, Mai, Nam, Tam). Owing to the absence of official, updated information from the government and health institutions, the parents

had to resort to unofficial sites and were often lost in a maze of information of sometimes questionable credibility. The large amount of information on the Internet also made it difficult for An and Nam to verify whether the information was valid, updated, and relevant to their children's condition (An, Nam).

Other parents of children with ASD served as another source of informational support. The parents connected with one another through their participation in offline sharing events coordinated by local autism clubs (An, Ba, Linh, Mai, Kim, Ly, Nam, Sang, Tam). Here, they shared ways to address their children's challenging behaviors and to take care of the children in daily activities (Kim, Linh, Ly). Sang described,

> The club usually organizes workshops where people [parents] come and share their experience and gave advice on treatment methods. Some families found methods that successfully reduced their children's challenging behaviors, while others had not, so the families who succeeded would stand up to share the methods to other parents. (Sang).

Ba and some other parents, whom he knew from an autism club, often met once every two weeks to discuss possible methods that could address their children's problems (Ba). According to Ba, "the small kids have a lot of [challenging] behaviors" with each child having their own idiosyncrasies. "One may like to wave a piece of paper back and forth like this." Ba illustrated the action and continued, "Others may like to do something else. How to stop such repetitive behavior? We [parents] sit down and discuss solutions together" (Ba). Similarly, Kim and some other mothers, with whom she attended the specialists' independent courses, also formed a group to brainstorm intervention strategies for their children (Kim).

In addition to offline meetings, the parents sought out to other parents through online forums and social networking sites for suggestions on treatments that had shown positive results

(An, Ba, Linh, Mai, Kim, Ly, Nam, Sang, Tam). Through online connections, the parents received materials—such as books and studies on autism and new intervention approaches—from other parents who travelled to countries with more developed research on autism (Mai). Parents who knew other languages also translated materials from abroad into Vietnamese and shared those materials on online forums, the autism clubs' websites, or their personal Facebook pages (Lan, Mai, Sang).

As noted in Chapter II, parents of children with autism often find advice from other parents who share their experience more applicable and acceptable than that from family members (Thoits 420). In the interviews, Ly and Nam likewise shared that their family members did not have much knowledge about autism, so they could not give the parents any useful information or advice (Ly, Nam). Past studies also indicated that parents who participated in support groups reported receiving helpful advice as well as information about developments in ASD treatments (Brobst, Clopton, and Hendrick 47; Papageorgiou and Kalyva 657; Reinke and Solheim 2368). The parents in this study affirmed that other parents not only helped them visualize specific steps to provide intervention for their children at home, but also answered their questions and alleviated concerns that other sources of information had not (Ly, Nam, Tam). As Samg explained, "Some of them [the parents] are doctors and researchers; some are good at foreign languages, so they have access to materials from developed countries like America and France." Those backgrounds enabled the parents to offer quality informational support to one another (Sang).

On the other hand, not all the informational support from other parents proved helpful. For instance, conflicting opinions might worsen a parent's uncertainty about suitable treatment for her child. "One person suggested a method, and I followed him," An said. "But then another

person told me that 'oh that method is outdated! It isn't applicable anymore!' and 'people are critical of it'" (An). The quality of such advice could also be questionable. An many times applied a method recommended by other parents to teach her son, but her child did not make any progress. When she took him to the doctor or consulted other sources of information, she found out that the method was only suitable to children with different symptoms of autism. The mother felt as if she were "groping around in a dark tunnel" (An). Nam also noted that "the children with autism were different from one another" and that "some principles and approaches may work for all of them [the children], but each child still has unique needs that only certain principles and approaches can meet" (Nam). Thus, Nam believed that although the advice from other parents was helpful, it was not equally applicable across the board.

Instrumental Support

Instrumental support includes goods, services, financial aid, labor, or time that enable recipients to complete a task successfully (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). For this study, instrumental support assists the parents in raising their children with autism. The parents listed seven providers of instrumental support: family members, the autism clubs, international organizations, professionals, the government, co-workers, and friends. Tam, a high school teacher, received instrumental support from her husband (Tam). "My husband is the main breadwinner," Tam noted. "So I don't have to teach too many after-school classes to earn more money and, therefore, have more time to care for our child" (Tam). Linh's parents, who lived far away from the couple's home, could not offer daily assistance but help them cover part of the expensive cost of intervention (Linh).

Nevertheless, seeking instrumental support from family members was not easy for all parents. Kim was proactive in gaining assistance from her family as she showed them how to react to her child's behaviors and how to communicate with the child (Kim). However, she found

instrumental support from family members limited because, with the exception of her husband, other family members "don't interact with the child that much, so they can only help to some extent" (Kim). Kim thought it was understandable because helping a child with autism was challenging for other people; she also felt that her family had no responsibility to gain thorough knowledge about ASD and ways to assist her child (Kim). Mai did not expect instrumental support from her family either because of her parents' advanced age and physical distance (Mai).

Other types of instrumental support either provided parents with practical training or organized social events for their children. Local autism clubs and a few private intervention centers offered free or low-priced courses that gave the parents essential skills to assist their children in multiple settings and situations (An, Ly, Mai, Sang, Tam). In addition, some professionals also opened independent training courses such as "languages used in communication with the children," "occupational therapy," and "pre-school preparation" (Kim). The courses enabled parents like Kim to visualize ways to interact with her child, to utilize treatment at home, and to help the child better adjust to school (Kim). Lastly, an international organization also offered instrumental support by funding local autism clubs to organize events such as a national sports festival for children with autism (Lan).

Although parents reported a lack of informational support from the government, they nevertheless received financial aid from the National Social Protection Department (Nam, Sang, Tam). However, the government's system of assessment and categorization also meant that not every child with ASD could obtain aid. For example, many children could only "receive a small monthly financial package, which amounts to a few hundred thousand dong [about $20 to $50]" if the committee of their district approved their application (Sang). Tam was aware of the financial aid that several children received, but she worried that her child might be rejected

because the child's symptoms of ASD were not as obvious as those of other children (Tam). Moreover, since "the national disability law does not recognize autism as a disability," stating one's children has autism might disqualify the application in the review process. This made Nam register his daughter, who has ASD, as a child with mental illness for her to be eligible for the aid (Nam).

Friends and co-workers also provided some instrumental help for the parents. Ly's company let her "come to the office an hour later in the morning and come home an hour earlier" so that she had more time to care for her son (Ly). Whenever Ly was busy, her friends came over to help her look after her son (Ly). Nam's co-workers also arranged to give the father more free time to spend with his daughter (Nam). While Mai did not specify any kind of instrumental support, the assistance of other parents in inviting special education teachers and coordinating class activities enabled Mai to run her small classroom for the six children with ASD (Mai).

Emotional Support

Emotional support refers to expressions of love, trust, care, empathy, and encouragement that reduce recipients' negative feelings (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). All parents in this study received emotional support, which included "sharing of thoughts and feelings," "expressions of sympathy," "encouragement," and "motivation," from two main providers: family members and other parents in the local autism clubs (An, Ba, Kim, Lan, Linh, Ly, Mai, Nam, Tam, Sang). Researchers agreed that emotional support from family members, especially spouses, was among the most helpful resources to cope with stress (Xue, Ooh, and Magiati 412-413). Past studies in the United States and Singapore also confirmed that immediate family is the most common source of support reported by parents of children with autism (Sharpley, Bitsika, and Efremidis 20; Xue, Ooh, and Magiati 412). In my own study, participants echoed such views. According to

Sang, "family members are closely connected, so they totally understand and empathize with the parents" (Sang). Ba also appreciated the emotional support given by his family, saying that both his and his wife's siblings were very caring (Ba). In seeking emotional support, the parents in this study often inclined towards intimate friends and family members rather than acquaintances and coworkers. Ly felt that "other people don't know what else they can do other than just offering some words of encouragement" (Ly). Worried that others' lack of understanding would lead to discrimination against her son with autism, An was reluctant to share her experience with acquaintances and coworkers (An).

Among family members, spouses provided the most emotional support to Kim and Mai. Whenever their child showed improvement after Kim and her husband applied an intervention method, the parents celebrated that accomplishment together, and both felt more confident in their child's future progress (Kim). Mai and her husband, Sang, also relied on each other for emotional support because they received sympathy from neither their parents nor other people. Mai said that her parents "don't understand anything about autism" and "even felt scared when seeing my son cry." Other people did not realize how trying the experience of Mai and her husband was, either because they "simply think that kids with autism just can't speak" or "don't know that kids with autism suffer from many disorders other than just language deficits" (Mai). She added, "It's very difficult for us but we don't receive anything or any encouragement. We can only rely on each other" (Mai). Mai felt happy about the support of her husband, Sang; she told me that she "could not ask for more" from him since he was the only person who worked and was under great financial pressures to sustain the family (Mai).

Lan even received emotional support from her daughter with autism. The mother recalled a time when she burst into tears because her daughter did not show any progress after months of

intervention. "One time I was really stressed and started crying in front of her because I could not bear the heavy pressures on my shoulders anymore." But her daughter's reaction surprised Lan. "She stood up and grasped a napkin to wipe my face; and she patted me and said what I often said to her, "Don't cry, mommy. I am here with you" (Lan). This affectionate gesture made Lan feel delighted because "I realized that it wasn't true that my daughter didn't listen to anything I taught her. She just had her own way of doing that" (Lan). The daughter's expression of love and care and her attempt to comfort her mother motivated Lan to stay hopeful about her daughter's progress and to remember that her constant efforts were not useless.

Besides family members, other parents in local autism clubs was another major source of emotional support for the parents in this study. As mentioned in Chapter II, Albrecht and Adelman found that individuals prefer seeking support from those they feel less uncertain about (20). The parents in autism clubs not only faced similar difficulties in raising their children with autism, but also interacted with one another frequently as they participated in the club's events together. As a result, the parents were more likely to share their experiences among themselves and to receive more quality support. Mai often went to the sharing events organized by an autism club to meet other mothers who had a child with autism. She believed that "only these parents can understand what my husband and I had been through and can give me better encouragement" (Mai). Tam agreed with Mai and hardly expected understanding from people who had not had similar experiences (Tam). Sang, Mai's husband, also found the emotional support from other parents helpful because "it's easier for us to sympathize with one another and to understand the odd behaviors of our kids which outsiders don't often tolerate." Therefore, Sang felt comfortable having his son go on a vacation with other families in his autism club rather than attend a company trip with his co-workers due to the lack of empathy among the latter (Sang).

In Chapter II, Goldsmith stressed the coherence between support providers' and recipients' understanding of the situation as a key determinant of effective support (*Communicating Social Support* 113). Parents who share the experience of raising a child with ASD could easily relate with one another and thus better understanding the distress as well as the needs for emotional reassurance of other parents (Thoits 420). Accordingly, the parents in local autism clubs might not only have higher motivation to offer emotional support to each other, but their support might also assuage other parents' stress more effectively. Ly gave a specific example of emotional support from other parents:

> I told other parents that my son had some problems and some unusual emotional
> expressions that I couldn't understand, and I felt really sad and stressed about it. Then
> people [other parents] told me examples of situations that were even worse than mine, but
> the mothers still kept an optimistic attitude. And they told me that if the mother is
> optimistic and happy, her child can feel it and will have less challenging behaviors. (Ly)

The optimism of parents who went through more difficult situations encouraged Ly to stay hopeful about her son's progress. An received a similar encouragement from other mothers. She noted, "They [the mothers] said to me that their children were in more serious conditions than my child was. But they said that after intervention, the children improved to that stage, so I should be patient and I could achieve it" (An). Such stories helped sustain the mother's hope in her child's treatment.

As previously discussed in Chapter II, support providers eliminate recipients' negative perception of an event by normalizing the stressful experience and encouraging recipients to believe that "they are not the only one" facing the situation (Brashers, Neidig, and Goldsmith 315; Scott et al. 398). Parents in their autism clubs utilized a similar strategy to comfort An and

Ly. Knowing that other parents faced more challenges when raising their children with ASD, An and Ly realized that their experiences were not unusual, and they felt reassured (An, Ly). To Ba, the presence of other parents whenever he needed them also gave him emotional support: "Sometimes when I felt sad, I called one or two other parents for a coffee talk, and we motivated each other" (Ba). The feeling that other parents were there for him surely gave Ba strength to move forward.

Although family members and other parents in local autism clubs were two major sources of emotional support, some parents reported other providers including specialists, friends, acquaintances, and co-workers (Ba, Kim, Lan, Nam). Lan remembered how the dedication of a specialist gave her motivation. Her daughter never cooperated with the specialist throughout the first three months of intervention. Lan described, "She always shrank herself and expressed a lot of repetitive behaviors and outbursts." But one day, when Lan came to pick up her daughter at the intervention center, a specialist ran to her. "The first thing he did was to hug me, and he congratulated me that my daughter finally cooperated," Lan recalled. "That happy moments of the specialist awoke me," she continued. "I realized that even a stranger like him, who traveled a thousand kilometers to get here, made great efforts to help my daughter and he did succeed" (Lan). Lan realized that, as a mother, she should be more patience and try harder to help her daughter. She then became more eager to expand her knowledge about autism to assist the therapists and teach her daughter at home.

In addition to emotional support from family and other parents, the parents received sympathy and encouragement from friends and co-workers (Ba, Kim, Nam). Co-workers sometimes let Ba get off from work early so that he would have more time to take care of his son. Ba was also happy that his son gained acceptance from other people. He shared that, "Some

parents met my son and knew that he was like that [had autism], but they still let their children [who did not have ASD] play with him" (Ba). Friends and co-workers often encouraged Kim to stay optimistic by reminding her of what her child had accomplished (Kim). For his part, Nam felt lucky that his friends, co-workers, and many other people were willing to listen to his thoughts and feelings and to give him encouragement (Nam).

Although An and Lan appreciated the reassurance that other people offered them, they did not request for any additional emotional support. The mothers believed that they could overcome the stress by themselves (An, Lan). An shared,

> Emotional support is important to many parents because some feel stressed and shocked. But perhaps I am a strong person that I just accepted the reality…. I always tell myself to keep trying until I succeed. I need to try every way to help my child. I never lose motivation. I just haven't found the suitable method for my child yet. But I don't feel discouraged, and I won't let the stressful feelings influence me either. (An)

Despite the numerous difficulties of raising a child with autism, An never wanted to give up. Nothing could prevent her from making constant efforts to help her child improve. Similarly, as someone who had raised her daughter with autism for almost twenty years and had provided tremendous support to many other parents, Lan became more resilient. "Why? Because we have been through the most terrible moments," Lan said. "I realize that we may feel sorrowful and stressed if we look at it from this angle; but if we view it from another perspective, we will see possibilities" (Lan). Lan learned to stay optimistic about her daughter's future, and she spread that positive attitude to many other parents.

Esteem Support

In Chapter II, proponents of the functional approach distinguished between emotional support and esteem support. While emotional support includes verbal or nonverbal expressions

of love, trust, care, empathy, and encouragement that alleviate recipients' negative feelings; esteem support refers to positive feedback on recipients' capabilities to cope with stress, which affirms the recipients' self-worth and self-competence (Cutrona 7; Cutrona, Suhr, and MacFarlane 31; Goldsmith, *Communicating Social Support* 13). However, the findings of my study suggested that the emotional and esteem support that the parents received were closely related rather than serving two distinct functions. The parents actually saw esteem support as an outcome of emotional support. When asked about esteem support, the parents listed "sharing of thoughts and feelings," "encouragement," and "sympathy" from others (Ba, Kim, Ly, Nam). Such support did not provide any direct feedback on the parents' capability; rather, it made the parents feel confident about their ability to help their children by reassuring the parents that they were not facing the stressful experience alone. Some parents also mentioned religious faith as a source of esteem support. Linh stated that, "Honestly, no one gives me that confidence." She explained, "Because I am a Catholic, I believe in our faith and our future, and I pray for it everyday" (Linh). An often chanted Buddhist texts because "reading those texts gave me inner peace" (An). She said, "I become fearless, and I am more hopeful about my child's improvement and everything" (An). Those parents who cultivated faiths drew strength from superpowers, thus feeling more courageous to face the difficulty.

The Parents' Requests for Additional Social Support

The social support that the parents in this study received was not adequate to eliminate their stress and uncertainty about their children's development, health improvement, and future adjustment to adult life. In the interviews, the parents listed their recommendations of helpful support that were not yet available to them.

Informational Support

All parents in this study were proactive in seeking informational support from multiple

sources. While some parents were satisfied with the informational support from professionals, the Internet, and other parents of children with autism (Ba, Ly, Mai), others found it insufficient (Kim, Lan, Linh, Nam, Sang). Kim, for example, attributed this inadequacy to the fact that "each child [with autism] is a unique individual" and "each has hundreds of problems that are different from those experienced by other children" (Kim). Acknowledging the variance of ASD symptoms and levels of severity across the diagnosed children, the parents wanted to receive recommendations of suitable intervention methods as well as instructions to apply those methods (Lan, Kim, Sang). Despite their access to information from other countries with advanced ASD treatments, the parents often had to learn and apply the suggested methods by themselves (Sang). It was difficult for them to evaluate which methods were suitable for their children without the proper instruction, supervision, and assessment of professionals and certified health organizations (Nam, Kim). Linh and Ly also requested additional informational support because they expected that many new problems would arise as their children grew older. For instance, when the children reached puberty, the parents would need advice from physicians and counselors on how to take care of adolescents with ASD (Linh, Ly). As previously discussed in Chapter II, past studies suggested that parents of children with ASD often have a high expectation of informational support from formal sources such as pediatricians, physicians, and therapists (Bromly et al. 419; DeMyer and Goldberg 237; Derguy, Michel, M'Bailara, Roux, and Bouvard 159-160). The parents in my study had a similar expectation. They believed that accredited professionals should be able to provide the parents with helpful information and advice on the children's condition and treatment (An, Nam, Kim).

Instrumental Support

Most of the support requested by the parents was instrumental support. They expected developments in intervention program, public education system, and vocational training and

employment programs that can support their children's development and adaptation to adult life. The parents also called for official legislation that recognized autism as a disability.

     Comprehensive Intervention Program. The parents wished to have a comprehensive intervention program that consisted of ongoing stages of treatment (Mai, Lan) and regular assessment of the children's progress (Tam). "We parents can't evaluate our children's condition and improvement by ourselves," Tam said. "We need assessment by physicians and therapists, as well as their recommendations on therapies that will address our children's existing problems" (Tam). The absence of this support forced An to utilize all treatment methods that other parents suggested to her, but those methods showed no positive result in her son's progress (An).

> People usually encourage me that "just be patient and keep teaching him. It's like boiling water in a kettle. If you keep on heating it, the water will be boiled." But I don't know until when it will happen. I don't see any of his progress … I set a goal that my son can speak, but it's been over a year since he was diagnosed and attended intervention center… but we still end up spinning our wheels. (An).

Because the children had different idiosyncrasies and degrees of disorders, their needs for treatment varied. As a result, the parents wanted assessment by professionals to design an individualized intervention plan that met each child's needs (An). Kim also added that Vietnam lacked a center that provided full intervention services, including speech-language, behavioral, and occupational therapies (Kim). She believed such a center would save parents' time and energy because they would no longer have to send their children to multiple places for comprehensive treatment (Kim). Ly supported the idea of a full-service intervention center because she believed that "it's important to have a multi-disciplinary team of professionals to support the children" (Ly). Ly's son not only had intellectual developmental problems, but also

experienced sleep disturbances, digestive disorders, and social communication deficits (Ly). However, Ly had not found any single center that could cover all of her son's needs (Ly). More importantly, the parents called for support from the government to supervise intervention programs for children with ASD (Lan, Tam). "I have more trust in the government to do so," Tam stressed. The large number of intervention centers of questionable credibility mentioned in the previous section appears to justify the parents' request.

In order to increase the effectiveness of professional assistance, An and Lan believed that the parents' active involvement in intervention for their children was necessary. An stated that special education teachers and health centers only provided short intervention sessions which lasted for two to three hours each day. Those sessions were not sufficient for the children because "the children need to get intervention twenty-four seven." An explained, "They need intervention when they go out, eat, sleep, [and] take a shower. They need it in everything they do" (An). Nonetheless, parents were still confused about how to implement intervention for their children in daily settings (An). Therefore, the parents needed training to assist the professionals better and to improve the outcome of intervention (An). Lan also emphasized the importance of the parents' role in treatment for children with ASD and gave an example of a parent-directed approach used by the Malaysian government. "All of its policies on autism focus on parents and the children's families," Lan described. "They teach the parents about early diagnosis, early intervention, daily support, [and] hourly support. They put the parents in the center, and social workers and physicians support the parents" (Lan). Lan wished that the Vietnamese government would follow a similar approach (Lan).

Public Education System. In addition to a comprehensive intervention program, the parents also found a public education system for their children with ASD desirable. The parents

believed that their children with autism deserved the right to go to school like many other children (Lan, Ly, Tam). Ly learned from parents who moved to live in Germany and the US that the children with ASD there had a separate school where they could learn academic knowledge (Ly). "The school also provided healthcare services for the children." Ly added, "Physicians, psychologists, and therapists were there to support the parents and the children" (Ly). While Vietnam had public schools for children with other disabilities, such as deafness, public schools for children with autism were nonexistent (Lan, Ly). Tam noted that such schools were more important for children with high levels of ASD severity because "studying at regular schools are greatly difficult for them" (Tam). Also, the large number of students in a regular classroom prevented teachers from providing sufficient assistance for students with autism (Tam). Thus, Tam sent her child to a private regular school, which had fewer students per classroom, so that her child could receive more attention from the teachers (Tam). However, the cost of private education was not affordable to all parents. Another alternative was to hire a private teacher to support the children's learning in regular classrooms (Ba, Kim, Linh). However, not many primary schools allowed the students with ASD to have a private teacher sit with them in class (Ly). According to Ba and Linh, only schools in "Hai Hong" District approved that option (Ba, Linh). Consequently, many parents thought of founding a school for children with ASD in Vietnam, but their inability to gather sufficient financial resources and to design a suitable curriculum for the children left the idea unimplemented (Lan, Tam). As Lan reflected, "We can do a lot of things for our children, but we can't build a school for them." Nonetheless, "our desire to have our children go to school never dies" (Lan). Once again, the parents requested support from the government to fulfill their wish (Lan, Ly, Tam).

Vocational Training and Employment. Besides intervention and education services for

the children, the parents expressed the need of vocational and employment programs that helped

individuals with autism find a job (Lan, Mai, Tam). Tam observed that many teenagers with

autism, whose parents were in the autism club, were talented: "They can draw, play musical

instruments, sew clothes, and embroider pictures on a fabric" (Tam). If these teenagers received

vocational training, they could "become helpful individuals who can contribute to the society"

(Tam). Mai also hoped that her son and other children with autism would have "a work

environment where they can socialize with others and do simple jobs that fit their abilities"

(Mai). Some parents actually ran small-scale vocational programs for their children with autism;

however, not many parents had sufficient financial capability to start and maintain such

programs. As a result, most of the parents in the autism club let the teenagers and young adults

with ASD stay at home (Lan, Tam).

Legal Recognition. Another form of instrumental support requested by the parents was

official legislation that recognized ASD as a disability (Ba, Lan, Nam). According to Lan, The

Social Security Department refused to include autism in the Disability Law because it lacked

resources to provide financial assistance for individuals with autism (Lan). Yet, financial support

was not the parents' main concern (Ba, Lan, Mai). Ba shared that his goal was not to receive

financial support from the government, but to prepare an "amulet" for his son (Ba). "In case my

son expressed any behaviors that may harm others, an official certification of disability would

grant him pardon or clemency," Ba explained. Nam appreciated the financial support that his

daughter received from the government; but more importantly, he wanted his daughter and other

children with ASD to gain protection under the law as other Vietnamese citizens (Nam). He said,

> None of our laws protects individuals with autism. You know that Vietnamese citizens of
>
> all occupations are under protection of specific laws. For example, you are a student, so

you have your rights, benefits, and responsibilities as a student specified in laws. But it's

not the case for individuals with autism. (Nam)

Nam also believed that the government's recognition of autism as a disability would not only

lead to enforcement of policies that benefited individuals with autism, but also encourage support

from other sources (Nam). Social campaigns promoted by the government would "make the

public realize that individuals with autism are part of the community, so our community has a

responsibility to support those individuals" (Nam). Thus, legal support from the government

would be a basis for the children with autism to gain public's acceptance and support.

Other Support. In addition to the aforementioned support, the parents wanted to receive

more assistance from their family members (An, Kim). Other people often assumed that mothers

would provide the best care and support for their children (Kim). However, An and Kim believed

that their children would have more opportunities to improve their behaviors if other family

members also apply intervention methods when interacting with the children (An, Kim).

The parents also requested special public services, such as playgrounds for the children

(Sang) and a nursing center for elders with autism (Tam). Accommodations for the children in

regular classrooms—such as exemptions from entrance exams and reduced workloads—were

also desirable (Kim).

Emotional Support

The parents considered the public's awareness about autism and acceptance of their

children with ASD the most important emotional support they would like to receive (An, Ba,

Lan, Linh, Mai, Sang, Tam). The parents hoped that other people would have a "correct

understanding of autism" (An, Ba, Lan) and would "sympathize with the children and their

families" (Linh, Tam). Lan shared that,

At least, people should not assume that the children have autism because their parents neglect them and don't care about them. They should understand that it [autism] is something the children were born with and will have to live with it forever. Even my daughter now still has many unusual behaviors, but those behaviors neither affect nor hurt anyone. (Lan)

The mother not only wanted the public to dispel the typical myths about autism, but also to accept the children with autism for who they were (Lan). Positive changes in perception would motivate other people to give more support to individuals with ASD (Lan, Tam). Lan said that "The support from other people could be really simple." She added, "If you know families who have a child with autism, let your children play with theirs. Such support is really precious" (Lan). However, An told me that her neighbors often felt reluctant to let their children play with her son because they were afraid that her son's unusual behaviors would affect their children negatively (An). She wished that her neighbors could be more sympathetic and supportive so that her son would have more chances to interact with the normally developing children. An believed that such interactions would facilitate her son's future inclusion in his adult life (An).

Conclusion

The parents' stress arose from the difficulty of getting intervention for their children with autism. The limited availability of public special education services forced the parents to seek treatment for their children at private centers. However, the expensive cost of those programs put great financial burdens on the parents. Due to their focus on early intervention for younger children, intervention programs often excluded teenagers and young adults with ASD. The parents also worried about their children's intellectual development and social inclusion. Some children could not study at regular schools due to their cognitive deficits, speech and language impairments, and complete dependence on assistance of others. Those who were able to attend

inclusive classrooms found it difficult to follow the class rules and to form meaningful relationships with the typically developing peers. Some regular schools even refused to include students with ASD into regular classrooms. Other sources of parental stress came from the lack of sympathy from the general public and the negative depiction of autism in public media.

While the parents in this study received social support from multiple sources, such support was insufficient. The parents reported many barriers to quality informational support such as the lack of qualified professionals in Vietnam, the limited access to professionals from abroad, and the questionable credibility of information from online sources. Instrumental support –such as training workshops for the parents—were on the verge of cessation owing the autism clubs' budget constraints. The exclusion of autism from the Vietnamese Disability Law also disqualified many children from receiving financial support from the government.

Accordingly, the parents called for additional social support to help them better assist their children with ASD. Most of the support requested by the parents was child-centered. In other words, the children with autism, rather than their parents, benefited from the support directly. However, as such support was important to the children's health improvement and social inclusion, the parents would reduce their stress and anxiety if given the support. Informational support including instructions on proper treatment that matched the children's unique needs and advice on how to care for an adolescent with autism was greatly desirable among the parents. The parents also demanded more instrumental support such as comprehensive intervention program and specialized school for individuals with ASD, vocational training and employment program that would give their children a job, and official legislation that recognized autism as a disability. Other instrumental support requested by the parents included additional assistance of family members, public services for individuals with

ASD, and accommodations for students with autism in inclusive classrooms. Lastly, public's understanding and acceptance of individuals with ASD was the parents' only desire for emotional support.

CHAPTER V: CONCLUSION

The purpose of my study was to examine the specific needs for social support of Vietnamese parents of children with ASD. In order to identify those needs, the study provided background on the parents' experience of raising a child with autism in Vietnam, examined the support that the parents received and their evaluation of it, and discussed the parents' self-reported requests for additional assistance. Although all parents in this study received social support from multiple sources, the support was insufficient to help them overcome the challenges of raising their children with autism. The parents expressed a great desire for additional support from the government, professionals, family, and the general public to facilitate their children's health improvement and inclusion in education, employment, and social settings. The following chapter will present my major conclusions, implications of these findings, limitations of the study, and recommendations for future research.

Major Conclusions

The study yielded four major conclusions. The first conclusion was that the parents' desires for informational, instrumental, and emotional support varied according to their children's age and level of ASD severity. While the parents shared many similar requests for informational and instrumental support, such as recommendations of intervention methods, instructions on how to apply those methods, and assessment of intervention outcomes, the parents of teenagers or young adults with ASD needed further assistance. In addition to ASD treatment, these parents also asked for advice on how to take care of adolescents with autism as well as vocational programs that could prepare their children for future careers. The parents of teenagers or young adults with ASD also had a higher need for emotional support that emanated from the public's understanding and acceptance of individuals with autism. As teenagers and young adults with ASD were approaching adulthood, support from people other than family

members became more and more important. The public's sympathy and acceptance could erase social stigmas and motivate supportive actions to include individuals with autism in employment and community settings, thus assuaging the parents' concerns about their children's adjustment to adult life and transition to independent living. Nonetheless, the parents of teenagers or young adults with ASD reported a lower need for direct encouragement from others than the parents of younger children did. Most of the children whose parents participated in this study were diagnosed early at the age of two; as a result, by the time of this study, the parents of teenagers or young adults with autism had already been through ten to fifteen years of taking care of their children. Instead of feeling stressed, impatient, or hopeless, these parents became resilient. They felt motivated to help their children and other families, especially those who were new to the experience.

The children's level of ASD severity was another factor that mediated the parents' needs for functional support. The parents of children with less severe autism wanted to receive more support from the school board and teachers to include their children in regular classrooms. Given such support, the children could both learn academic knowledge and socialize with typically developing peers. After intervention, the children with less severe autism often showed improvement in their intellectual and social communication abilities, which enabled them to learn at regular schools if given sufficient assistance. In contrast, the children with severe autism could not study at regular schools because of their serious cognitive disorders and inability to speak. Thus, the parents of these children placed a higher priority on specialized schools that provided effective treatment and taught the children essential life skills to care for themselves in daily activities.

Second, the study concluded that instrumental support was the most desirable type of

functional support for the parents. Not only did the parents request instrumental support most often, but they also asked for more diverse types of instrumental support. Other than developments in intervention programs and the public education system for children with autism, the parents called for vocational programs that would give the adults with autism a job and official recognition of autism as a disability. Instrumental support could also resolve the parents' needs for informational, emotional, and esteem support. For instance, the lack of qualified physicians and healthcare professionals for children with ASD in Vietnam was a barrier that impeded the parents' access to credible sources of information. Instrumental support such as an education and training system for health professionals would certainly improve the quality of informational support that the parents would receive in the future. The parents' hope for the public's understanding and acceptance of their children with ASD also implied a need for instrumental support from the government and public media to raise awareness about the disability and to encourage support for individuals with autism. Furthermore, helpful instrumental support could fulfill the parents' emotional needs because it would reduce the parents' uncertainty about their children's health improvement and ability to live independently. Lastly, helpful instrumental support from a myriad of sources –such as the government, professionals, other parents, family, and friends—could make the parents feel more confident in their capability to help their children improve, thus enhancing the parents' self-esteem.

Third, the study discovered the significant role of other parents of children with ASD in providing support for the ten participants. Other parents who also had a child with autism were the only provider who offered the parents all five types of functional support, which included network, informational, instrumental, emotional, and esteem support. The parents of children with ASD often came together in either small or large groups. They not only introduced

physicians and therapists to other parents, but also shared helpful materials about ASD treatment, and expressed sympathy and encouragement with each other. The tremendous mutual support from people who shared their experience gave the parents motivation, hope, and confidence to carry on.

Finally, my study recognized the parents' high expectations for social support from the Vietnamese government. Despite their strong support networks in the local autism clubs, the parents could not provide all of the needed support by themselves. Only the government had sufficient resources and authority to implement changes in areas such as public health, education, and policies to support individuals with ASD. In their requests for additional support, the parents trusted that the government could provide reliable sources of information and supervision of intervention programs. They also wished for support from the government to develop a specialized public education system for children with ASD and to enact legislation that recognizes ASD as a disability. Indeed, the parents called for immediate and direct actions from the government to provide support for individuals with ASD and their families.

Implications of the Research Findings

My study had several implications, as well. First, the findings of this study suggest an interconnection among different types of functional support. Rather than having a distinct function, each type of support can contribute to the impact of other support types. Network support plays an important role in the relationships among types of functional support because it is the root of four other support types. In other words, network support, which widens recipients' connections to potential support providers, is the means through which recipients obtain informational, instrumental, emotional, and esteem support. For instance, the parents in this study received network support from professionals and other parents to connect with physicians,

therapists, and special education teachers. These individuals then provided the parents with informational support, such as advice on ASD treatment; instrumental support, such as training workshops and financial assistance; and emotional support, such as sympathy and encouragement.

The interconnection of types of social support manifests itself in the overlapping functions of informational, instrumental, emotional, and esteem support. In the earlier section, I discussed how instrumental support could enhance the quality of informational support through education and training systems for support providers. Practically, informational and instrumental support could also generate emotional and esteem support. For instance, the parents in this study could feel less stressed and more confident in raising their children with autism when given helpful information about ASD treatment and practical instructions on ways to utilize the information effectively. Instrumental support from family and friends also comforted the parents because it made the parents realize that they were not facing their stressful experience alone. Additionally, emotional support could have the function of esteem support. The encouragement from others that reminded the parents of their children's accomplishments surely reinforced the parents' confidence in their ability to help their children improve. Indeed, researchers should attend to the interconnection among the five support types to avoid rigid distinctions and oversimplifications of the impact of functional support.

Second, this study confirms the need to integrate both structural and functional approaches to studying social support. As previously mentioned in Chapter II, proponents of the functional approach evaluated the effectiveness of social support based on whether the types of given support matched individuals' specific needs (Cutrona 8-10; Pierce, Sarason, and Sarason 177). However, the findings of my study imply that an optimal match between support types and

needs is not the only determining factor. Researchers should also examine favorable properties of support networks that grant recipients access to helpful support. For instance, the large size of local autism clubs could increase the sources of informational support for members as well as the amount of money donated by parents to invite professionals and organize annual events. Moreover, the frequency of interactions among parents who coordinated activities and participated in workshops together could increase the intensity of the parents' network, thus allowing the parents to know each other better and to build more stable, supportive relationships with other parents. Compared to other social networks such as family, friends, and co-workers, the network of parents in the local autism clubs had a higher homogeneity relating to the experience of raising a child with autism. This commonality made it easier for members in the parents' network to understand the stress and needs for support of one another, thus offering more helpful assistance. Therefore, besides matching the types of support to individuals' needs, we should see if social networks in which the support seekers participate have advantageous characteristics that facilitate the desired support.

Another important factor to consider is the network members' ability to offer helpful support or to activate the support that they receive from others. For instance, the parents in this study received informational support from ASD professionals such as physicians, therapists, and special education teachers. However, not all of the informational support from these providers was helpful because many professionals lack both a thorough understanding about autism and certification in ASD therapy. While the parents received a lot of materials about ASD treatment, they had to interpret and apply the information themselves. Without specialized knowledge in autism and instructions from health professionals, the parents might find it difficult to understand technical terminologies and concepts and to apply the suggested methods effectively.

Last but not least, this study calls for support from the government and non-governmental organizations to assist support groups for parents of children with ASD. While support groups, like the local autism clubs, proved effective in helping parents overcome their stressful experience of raising a child with autism, these groups were not sustainable due to several shortcomings. Most parents who volunteered to coordinate events of the local autism clubs also had their full-time jobs. The heavy dual responsibilities put great pressures on these parents and reduced their available time to take care of themselves and their children with autism. Therefore, the parents were in need of administrative and operational assistance from a third-party organization to maintain the support groups. Also, the budget for the autism clubs mostly came from donations of the parents, who were just regular employees with average incomes. Given the expensive cost of intervention for their children and many other living expenses for the families, the parents had little financial capability to maintain their sponsorship of club events. Thus, financial support from the government or donor agencies is necessary for support groups, like the autism clubs, to sustain themselves and to flourish.

Limitations

Despite its contributions to research on social support for parents of children with autism, the study still has certain limitations. First, my study sample was not representative of all Vietnamese parents of children with ASD in urban areas. Similar to other qualitative research, my sample included a small number of participants. Since most of the participants were female, the mothers' voices were more dominant than those of the fathers. Also, all parents in this study received helpful support from the local autism clubs in which they participated, so their needs for social support would be different from those who did not have access to any support groups, as well as those who did not find the support groups beneficial.

Second, although my study gained insights into the kinds of support that the parents

received and those that the parents desired, it did not explain communicative patterns that influenced the support transactions. In other words, I could not examine the actual messages that the parents used to describe their experience and to express their needs. Neither could I observe how others interpreted those messages and communicated support to the parents.

Recommendations for Future Research

Given the major conclusions, implications, and limitations of my study, I have three recommendations for future research on this topic. First, I recommend observing the parents' interactions in sharing events, online forums, and social networking sites. An examination of the actual support transactions among the parents would allow researchers to identify supportive messages and effective strategies that the parents utilize to communicate support to one another.

Second, future researchers should interview both formal support providers –such as physicians, therapists, and special education teachers—and informal support providers—such as family members, co-workers, and friends—to ask about their opinions on social support for the Vietnamese parents of children with ASD. Through such interviews, researchers should try to understand the support providers' willingness and ability to offer social support to the parents, as well as the barriers that prevent them from providing the support that the parents desire.

My last recommendation would be to conduct a study on Vietnamese parents of children with ASD in less developed locations in the country. Compared to the parents in the cities, parents who live in suburban or rural areas often have lower incomes and education levels. They also lack supportive resources such as intervention and other health services for individuals with autism and parent support groups like the local autism clubs. Therefore, the parents in those areas would have a higher need for social support than the parents in my study.

Final Thoughts

It has been over 20 years since the number of ASD diagnosed cases started to rise in Vietnam, but the support given to parents of children with autism remains inadequate. The limited availability of qualified health and education services for individuals with autism and the public's ignorance about the disability are two main causes of the stress and anxiety that Vietnamese parents of children with ASD experience. Similar to many other parents in local autism clubs, the parents in this study have been proactive in seeking support from various sources and in offering support to one another. Besides their role as parents, they served not only as teachers and therapists for their children with autism, but also as fundraisers, organizers, and social activists through their participation in local autism clubs. The unconditional love for their children surely gave the parents strength and motivation to overcome many challenges of raising their children with ASD. However, the parents could not fulfill all of their children's special needs by themselves because of their limited financial capability and authority.

Observing my parents throughout their four years taking care of my youngest sister with autism, I understand how uncertain, stressed, exhausted, and disappointed Vietnamese parents of children with ASD may feel given their challenging experience and the insufficient social support that they receive. Different from the parents in this study, my parents and many other parents whom I met during my visits to several private intervention centers neither knew nor participated in any support groups for parents like the local autism clubs. Those parents might experience more difficulties due to their lack of assistance from one of the most helpful sources of support for Vietnamese parents of children with autism.

Through this study, I hope to inform the Vietnamese government, non-governmental organizations, support groups, and the general public of the inadequate support given to

individuals with ASD and their families. My study could not fulfill its meaning if no action in response to the parents' needs is taken. Even though we know that change is often a gradual process, we also understand that each of us can contribute to that process in a variety of ways. Supporting individuals with ASD and their families may come from the simplest acts such as educating ourselves on the disability, communicating correct messages about autism to others, or assisting individuals with autism in education, employment, and social settings. Further than that, immediate actions by the government to revise legislation and to enact policy on support for individuals with autism and their families, as well as collaboration of support providers across health, education, and social security sectors are greatly important. I believe that, as citizens of Vietnam, individuals with ASD deserve the right to legal protection, comprehensive intervention, inclusive education, and other essential support to flourish.

It was my pleasure to have the opportunity to know and to learn from the ten parents who participated in this study. I admired the constant, unwavering efforts that they have been making not only to help their children but also to support other families of children with ASD in Vietnam. This study is dedicated to those courageous parents. I thanked them for sharing with me their stories and for enabling me to conduct research on an issue about which I deeply concern. They were also an inspiration for my family to never give up on my sister with autism.

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APPENDIX A: INTERVIEW QUESTIONS

1. How old are you?
2. How many members are there in your family?
3. What is your job? Where are you working?
4. How many children do you have? Which of them is diagnosed with Autism Spectrum Disorders (ASD)? When was he/she diagnosed with ASD? What is his/her current health condition?
5. Before your child was diagnosed, did you know anything about ASD? What did you know? How did you find out the information?
6. Is your child with ASD participating in any treatment or intervention services? If yes, what are they? How did you learn about these services? How often does your child participate in those services? How long has he/she been participating in those services? Do you think the services are helpful to your child? Why or why not?
7. Does he/she go to a regular school? Why or why not? If your child does goes to a regular school, how has that experience been for your child academically? Socially? Any other ways?
8. How could you describe your experience of raising a child with ASD? How does having a child with ASD affect you and your family? Are there any issues that have been particularly challenging? If so, how? If not, why not?

Because a lot of people in Vietnam refer to social support as social welfare, I will clarify how my study uses the term differently before asking the parents about social support. I will give the parents a notecard that explains the concept of social support in my study. The content of the notecard is as follows:

> Social support is assistance provided through communication to help individuals cope with stress. People who provide support may include professionals such as doctors, educators, and coworkers, and also family members and friends.

Then, l will ask the parents if they have any question about this concept. After the parents understand what I mean by social support, I will continue the interviews with the below questions.

9. Informational support is a kind of social support that provides needed information, guidance, suggestions, or advice for recipients to cope with the stressful situation.
   a. Have you ever received this type of support while raising your child with ASD? Why or why not?
   b. What informational support do you receive?
   c. From whom do you receive this kind of support? How would you describe your relationships with the support providers?
   d. How would you evaluate the support that they give you? Is there any way that you would suggest these individuals improve the support they provide?
10. Emotional support involves expressions of love, trust, care, empathy, and encouragement that help alleviate recipients' negative feelings and motivate their positive ones.

    a. Have you ever received this type of support while raising your child with ASD? Why or why not?

    b. What emotional support do you receive?

    c. From whom do you receive the support? How would you describe your relationships with the support providers?

    d. How would you evaluate the support that they give you? Is there any way that you would suggest these individuals improve the support they provide?

11. Instrumental support is a kind of social support that provides devices, services, money, or time that are essential for recipients, in this case, to raise their child with ASD.

    a. Have you ever received this type of support while raising your child with ASD? Why or why not?

    b. What instrumental support do you receive?

    c. From whom do you receive the support? How would you describe your relationships with the support providers?

    d. How would you evaluate the support that they give you? Is there any way that you would suggest these individuals improve the support they provide?

12. Esteem support is social support that offers reassurance by giving positive feedback on individuals' capabilities to cope with stress.

    a. Have you ever received this type of support while raising your child with ASD? Why or why not?

    b. What esteem support do you receive?

    c. From whom do you receive the support? How would you describe your relationships with the support providers?

    d. How would you evaluate the support that they give you? Is there any way that you would suggest these individuals improve the support they provide?

13. Network support refers to social support that provides recipients with networks of professionals and/or groups who are able to help them overcome the stressful situation.

    a. Have you ever received this type of support while raising your child with ASD? Why or why not?

    b. What network support do you receive?

    c. From whom do you receive the support? How would you describe your relationships with the support providers?

    d. How would you evaluate the support that they give you? Is there any way that you would suggest these people improve the support they provide?

14. Is there any other support that you receive but we have not talked about? If yes, what is the support? From whom do you receive the support? How would you describe your relationships with the support providers? How would you evaluate the support they give you? Is there any way that you would suggest these people improve the support they provide?

15. What support is the most important to you? Why?

16. What support is the least important to you? Why?

Is there a kind of support you wish you had, but which is unavailable to you right now? Could you please explain?

1. Recruitment Phone Script:

Hi [insert name],

My name is Khue Hoang, and I am a senior in Communication Studies at The College of Wooster. I am working on research for my senior thesis and would like to learn more about the support from others that Vietnamese parents who have a child with autism want to receive. I received your contact information from a parent who thought you might be interested in my study.

Your participation is greatly valuable because it would help professionals and support groups in Vietnam gain deeper insights into your experience and allow them to develop suitable programs that address the needs for support of Vietnamese parents of children with autism.

If you decide to participate in this study, you will be asked a series of questions regarding your experience of raising a child with autism and your needs for support from others. While I will need to record the interview, I will hold your responses to interview questions confidential and will never reveal your actual identity.

This study is voluntary, so if you would like to participate, I will send you an email with more detailed information about the study and the interview process. If you have any questions, please feel free to contact me at (xxx) xxx-xxxx or khoang17@wooster.edu. I would greatly appreciate your participation. Thank you so much.

2. Recruitment Emails:

Dear [insert name],

My name is Khue Minh Hoang. I am a senior in Communication Studies at The College of Wooster. I am writing to invite you to participate in my research about the needs for support from others that Vietnamese parents who have a child with autism want to receive.

If you decide to participate in this study, you will be asked a series of questions regarding your experience of raising a child with autism and your needs for support from others. Your participation in this study is greatly valuable because it can help professionals and support groups in Vietnam gain deeper insights into your experience, thus allow them to develop suitable programs that address the needs for the support of Vietnamese parents of children with autism.

I would like to record the interview so that I can use the information you provide me to enhance my study. However, your responses to interview questions will be held confidential. At no time will your actual identity be revealed. The interviews will be audio-recorded by using a password-protected smartphone. The audio recordings will also be stored on a password-protected laptop. I will delete the recordings off the smartphone and laptop after they have been transcribed. In Vietnam, I will keep the interview transcripts, without your name, in a document safe. Once back in the United States, I will keep the transcripts in my locked carrel drawer at Timken Library.

After the study is complete, I will destroy the transcripts with a paper shredder. In my study, I will use fake names to refer to you, people, and places that would identify you.

This study is voluntary, so if you would like to participate or have any questions about the study, please email me at khoang17@wooster.edu, or contact me at (xxx) xxx-xxxx. I would greatly appreciate your participation.

Thank you so much for your time and concern.

Best regards,
Khue Minh Hoang

APPENDIX C: CONSENT FORM

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

COLLEGE OF WOOSTER

Vietnamese Parents of Children with Autism Spectrum Disorders and Their Needs for Social Support*
 * Social support is assistance provided by professionals such as doctors, educators, or co-workers, and/or by family members and friends to help individuals cope with stress.
Principal Investigator: Khue Hoang/ Communication Studies Major

Purpose
You are being asked to participate in a research study. I hope to learn more about the needs for social support of parents of children with autism in Hanoi, Vietnam. The data will be used for a senior independent study thesis at The College of Wooster.

Procedures
If you decide to volunteer, you will be asked to answer a number of questions about your experience of raising a child with autism and your needs for social support. Each interview will take about 45 to 60 minutes to complete. The interview will be recorded.

Risks
There are no risks to you participating in this study.

Benefits
There are no benefits to you participating in this study. However, it is my hope that the insights gleaned from this research may ultimately help professionals and support groups in Vietnam better understand the experience of parents of children with Autism in order to develop suitable programs that address the parents' needs for social support.

Storage Data
The interviews will be audio-recorded by using a password-protected smartphone. The audio recordings will also be stored on a password-protected laptop. I will delete the recordings off the smartphone and laptop after they have been transcribed. In Vietnam, I will keep the interview transcripts, without your name, in a document safe. Once back in Wooster, I will keep the transcripts in my locked carrel drawer at Timken Library. After the study is complete, I will destroy the transcripts with a paper shredder.

Confidentiality
Your responses to interview questions will be held confidential. At no time will your actual identity be revealed. You will be assigned a random numerical code. The code linking your name with your number will be stored in a password-protected laptop. This file will be destroyed once the study is complete. In my study, I will use fake names to refer to you, people, and places that would identify you.

Costs/Compensation
There is no cost to you beyond the time and effort required to complete the procedure described above. There will be no compensation for your participation.

Right to Refuse or Withdraw
You may refuse to participate in the study. If you decide to participate, you may change your mind about being in the study and withdraw at any point during the interview with no negative consequence. Participants also have the option not to answer any question(s) that they are not comfortable answering.

Questions
If you have any questions, please ask me. If you have additional questions, you can contact me by email at khoang17@wooster.edu or by phone at 01629860371. You also may contact my advisor, Dr. Denise Bostdorff, at dbostdorff@wooster.edu.

Consent
Your signature below will indicate that you have decided to volunteer as a research participant, that you have read and understand the information provided above, and that you are at least 18 years of age.

Printed name of participant_____

Signature of participant_____Date_____

You will be provided a copy of this form upon request.

GIẤY CHẤP THUẬN THAM GIA NGHIÊN CỨU
ĐẠI HỌC THE COLLEGE OF WOOSTER, OHIO, HOA KỲ

Đề tài nghiên cứu: Phụ Huynh của Trẻ Tự Kỷ tại Việt Nam và Nhu Cầu Nhận Trợ Giúp Xã Hội*
 * Trợ giúp xã hội là sự giúp đỡ từ chuyên gia như bác sĩ, nhà giáo dục, đồng nghiệp, hoặc từ   gia đình và người thân để hỗ trợ cá nhân vượt qua một giai đoạn khó khăn trong cuộc sống.
Người thực hiện: Hoàng Minh Khuê/ Chuyên ngành nghiên cứu truyền thông

Mục Đích

Quý vị được yêu cầu tham gia một nghiên cứu. Qua nghiên cứu này, tôi mong muốn sẽ hiểu hơn về nhu cầu được nhận trợ giúp xã hội của các bậc phụ huynh có con mắc chứng rối loạn tự kỷ tại Hà Nội, Việt Nam. Dữ liệu từ nghiên cứu này sẽ được sử dụng trong đề án tốt nghiệp của người thực hiện tại trường đại học The College of Wooster.

Quy Trình

Nếu Quý vị tình nguyện tham gia, Quý vị sẽ được yêu cầu trả lời các câu hỏi về những trải nghiệm của mình trong việc nuôi dạy trẻ tự kỷ, và nhu cầu được nhận trợ giúp xã hội của Quý vị. Mỗi cuộc phỏng vấn sẽ được tiến hành trong vòng từ 45 đến 60 phút. Cuộc phỏng vấn sẽ được thu âm.

Rủi Ro

Quý vị không có bất kỳ rủi ro nào khi tham gia nghiên cứu này.

Lợi Ích

Quý vị sẽ không nhận được lợi ích trực tiếp nào khi tham gia nghiên cứu này. Tuy nhiên, tôi hi vọng rằng những thông tin thu nhận được từ nghiên cứu sẽ mang đến những thông tin hữu ích cho các chuyên gia và các nhóm trợ giúp xã hội ở Việt Nam hiểu hơn về những điều mà phụ huynh của trẻ tự kỷ đang trải qua. Từ đó, các cá nhân và tổ chức này có thể xây dựng những chương trình phù hợp giúp phụ huynh Việt Nam nhận được những trợ giúp xã hội mong muốn.

Lưu Trữ Thông Tin

Nội dung cuộc phỏng vấn sẽ được ghi âm lại bằng một điện thoại thông minh có đặt mật khẩu bảo vệ. Bản ghi âm cũng sẽ được lưu trữ trong một máy tính có đặt mật khẩu bảo vệ. Tôi sẽ xóa bản ghi âm trong điện thoại và máy tính sau khi chuyển dịch bản ghi âm sang văn bản đánh máy. Tại Việt Nam, văn bản đánh máy lưu trữ nội dung phỏng vấn sẽ được tôi cất trong két sắt cá nhân. Khi quay trở lại Hoa Kỳ, những văn bản này sẽ được khóa trong ngăn kéo tại bàn làm việc của tôi tại Thư Viện Timken. Sau khi hoàn tất nghiên cứu, tôi sẽ hủy toàn bộ văn bản đánh máy bằng máy hủy tài liệu.

Bảo Mật

Câu trả lời của quý vị đối với các câu hỏi phỏng vấn sẽ được bảo mật hoàn toàn. Danh tính của Quý vị cũng sẽ không bao giờ được tiết lộ. Quý vị sẽ được cấp cho một mã số bất kỳ, và mã số này sẽ đại diện cho tên của Quý vị trong quá trình văn bản đánh máy buổi phỏng vấn được sử dụng để phân tích. Mã số này được lưu tại một máy tính có mật khẩu bảo vệ. Tệp này sẽ được xóa khi nghiên cứu hoàn tất. Trong nghiên cứu của mình, tôi sẽ sử dụng tên giả thay cho tên của Quý vị, và những người hay địa điểm mà từ đó có thể xác định danh tính của Quý vị.

Phí Tổn/Đền Bù

Không có chi phí nào cần thiết ngoài thời gian và công sức Quý vị dành cho buổi phỏng vấn này. Không có khoản đền bù nào dành cho sự tham gia của Quý vị.

Quyền Từ Chối Hoặc Chấm Dứt Tham Gia

Quý vị có quyền từ chối tham gia nghiên cứu. Nếu Quý vị quyết định tham gia và muốn chấm dứt tham gia trong quá trình thực hiện nghiên cứu, Quý vị có thể dừng việc tham gia tại bất kỳ thời điểm nào của cuộc phỏng vấn. Không có bất cứ thiệt hại và hậu quả gì khi quý vị chấm dứt tham gia nghiên cứu. Quý vị có quyền từ chối trả lời những câu hỏi mà Quý vị cảm thấy không thoải mái khi đưa ra câu trả lời.

Câu Hỏi

Nếu Quý vị có bất kỳ câu hỏi nào trong quá trình phỏng vấn, xin hãy hỏi trực tiếp tôi. Nếu Quý vị còn có những câu hỏi khác, Quý vị có thể liên hệ với tôi tại địa chỉ email khoang17@wooster.edu hoặc qua số điện thoại 01629860371. Quý vị có thể liên hệ với Giáo Sư Hướng Dẫn Nghiên Cứu của tôi, Tiến sĩ Denise Bostdorff, tại địa chỉ email dbostdorff@wooster.edu.

Chấp Thuận

Chữ ký của Quý vị dưới đây sẽ xác nhận rằng Quý vị đã chấp thuận và cam kết tự nguyện tham gia nghiên cứu này. Chữ ký của Quý vị cũng xác nhận Quý vĩ đã đọc và hiểu những nội dung được cung cấp phía trên và Quý vị là người có độ tuổi từ 18 trở lên.

Tên người tham gia (in hoa) _____

Chữ ký người tham gia _____Ngày ký _____

Bản sao văn bản này sẽ được cung cấp cho Quý vị nếu Quý vị yêu cầu.