

The Effect of Dohsa-hou

The Effects of Dohsa-hou: Parental Perspectives

by

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfillment of the requirements of the degree of

DOCTOR of PHILOSOPHY

Faculty of Education

University of Manitoba

Winnipeg

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### **Abstract**

Our understanding of autism has changed a great deal since the 1940s. Old ideas about autism, and how to respond to it, have evolved. New ideas about the cause of autism and its treatment have emerged. One challenge for families and educators is to identify the approaches that are appropriate and effective for the children they support. During my Master's program in South Korea, I was introduced to the use of dohsa-hou as a new and different conceptual approach to children with autism spectrum disorders (ASD). The effectiveness of the approach has been discussed in books (Kumar, Harizuka, Furukawa, Kim, & Kumar, 2005; Kim, Lee, Kwak, & Baek, 2001), in a variety of studies (Kouno, 2005; Konno, 1993; Toya, 2003), and at practical camps sponsored by professionals using the approach. Although it has been used mostly by professionals, parents have been introduced to dohsa-hou and encouraged to use it at home. I want to document and analyze parental perspectives on their experiences with this approach.

In this study, I include a discussion on how ASD has been understood, responses to ASD considered from an empirical standpoint, and explain how dohsa-hou relates to other prevalent responses to ASD. To examine parental perspectives on the dohsa-hou approach, I completed in-depth interviews with twenty-one parents who have been using dohsa-hou at least for one year (eleven parents from South Korea and ten parents from Japan). I asked parents if taking part in dohsa-hou affects the relational behaviours of their children with ASD. For example, the perspectives of the parents were sought in order to examine: 1) any possible relationships between the approach and their children's behaviours such as listening to others, initiating communications, interacting with others, and participating in tasks, and 2) if they thought their children's self-awareness of their body image and frame changed during and after dohsa-hou (e.g.,

posture, movement, and bodily self-awareness).

The parents in this study shared their personal stories as well as their thoughts on ASD and their child. The parents did not limit their thoughts to ASD and dohsa-hou. They also thought their children should obtain better supports for a better life in general. For the parents in this study, this not only meant a better education and better in-school support, but also community acceptance and support. The findings showed that dohsa-hou is not only helpful for children with ASD, but also helps their parents and other people to understand and support children with ASD and help them to have better lives in the community. Finally, the findings suggest that dohsa-hou is not just focused on ASD itself but the whole person.

### **Acknowledgements**

I would not be able to have this journey without many people's guidance and support. I would like to express my special appreciation and thanks to my advisor Professor Dr. Zana Lutfiyya, you have been a tremendous mentor for me. I would like to thank you for encouraging my study and for allowing me to grow as a researcher. Your academic and emotional support has been priceless. I would also like to thank my committee members who provided academic, emotional and editorial support throughout the completion of this thesis: professor Dr. Rick Freeze, Dr. Emily Etcheverry and Mrs. Mary-Ann Updike. THANK YOU for serving as my committee members even at hardship!

I would like to acknowledge participants, translators and editors who took part in this study to express my big thank. All of you have offered tremendous work for me. I cannot thank enough to your sincere, earnest and genuine support.

I would also like to acknowledge my family for all of the sacrifices that you have made on my behalf: my parents Kisoo Bang and Mia Lee, my sisters Joeun and Cheonjong Bang, my brother Kyoungjoo Bang, my husband Heeseop Yang and my son Nathan Taegyung Yang. Your prayer for me was what sustained me thus far. I would not be able to complete this thesis without their support. I would also like to thank all of my friends who supported me emotionally to strive towards my goal.

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## **Chapter I**

### **Introduction**

Our understanding of autism has changed a great deal since the 1940s. Old ideas about what autism is and how to respond to it have evolved. New ideas about the cause and nature of autism, and how to respond to it, have emerged. One challenge for families and educators is to identify the approaches that are appropriate and effective for the children they support. During my Master's program in Special Education in South Korea, I was introduced to the use of dohsa-hou as a new and different conceptual approach to children with autism spectrum disorder (ASD). The effectiveness of the approach has been discussed in books (Kumar, Harizuka, Furukawa, Kim, & Kumar, 2005; Kim, Lee, Kwak, & Baek, 2001), in research studies (Kouno, 2005; Konno, 1993; Toya, 2003). Dohsa-hou is also practical at camps where supervisors, trained practitioners, interning students, children with ASD and their families use the approach. Although used by professionals as an intervention, parents also have been introduced to dohsa-hou and encouraged to use it at home.

The research into dohsa-hou has been carried out primarily at Kyushu University in Japan by Dr. Gosaku Naruse and his colleagues. They have focused on the efficacy of dohsa-hou. While not all parents use dohsa-hou with their own children, parents have been responsible for having their children exposed to dohsa-hou. The perspectives of the parents have not been documented, a gap that I address. In this study, I focused on what parents thought about how dohsa-hou has, or has not, worked for their children with ASD, and how they have come to understand the approach and its impacts, if any, on their children.

### **Introduction to Dohsa-hou**

Dohsa-hou has been introduced and used only in some Asian countries to date. However,

it has remained largely unknown in North America. The literature on dohsa-hou is published in Japanese and Korean, with very limited publication in English. Dohsa-hou is a method of psychological rehabilitation developed by Dr. Gosaku Naruse in Japan (1966). Naruse defined dohsa-hou as a therapeutic intervention to promote more appropriate self-regulated activities, including self-control, by means of ‘dohsa’ (action) and ‘hou’ (method). The goal is to achieve intentional body movements (Naruse, 1995). The earliest applications of dohsa-hou were focused on individuals with cerebral palsy. Later, research by Konno and Ohno (1987) focused on the utilization of the dohsa-hou method to treat children with ASD and hyperactivity. Dohsa-hou conceptualizes body image as a psychological construct that relates to the feelings and attitudes one has about one’s own body. According to the proponents of dohsa-hou, a ‘body image’ is created in a person’s mind based on the body’s physical experiences with muscle tension and relaxation. In other words, by perceiving a differential sense of muscular activities, a person can recognize their body as their own, and experience an appropriate relationship between mind and body. Consequently, the psycho-rehabilitative method of dohsa-hou is thought to increase sensitivity to the physical processes of the body as well as to increase the individual’s awareness of ‘body image’. At this point, dohsa-hou might appear like yoga to observers because both methods use relaxation techniques. The differences between them are that the concept of dohsa-hou is based on a therapeutic approach and that the concept of yoga is based on spiritual practice with a particular religious background. The application of the dohsa-hou method to children with autism has demonstrated improvements in the areas of personal interactions and eye contact (Lee & Cho, 2002; Konno & Ohno, 1987). Coincident with applications of dohsa-hou, researchers have observed remarkable behavioural changes in individuals with ASD, such as reduced hyperactivity and perseveration, reduced panic, and the expansion of their social behaviour and linguistic abilities (Morisaki, 2005; Kim et al., 2001; Konno, 1993; Yamamoto, 1992). Oda and

Tani (1994) studied positive effects of dohsa-hou towards learning activities and communication.

The current definition of ASD of the Diagnostic and Statistical Manual 5 (DSM-5) (American Psychiatric Association, 2013) states that persistent deficits in social communication and social interaction, along with restricted and repetitive patterns of behaviours or interests, must be presented from early childhood. These symptoms must limit and impair the everyday functioning of the affected individual (APA, 2013). Existing treatment studies have shown that the behaviours of individuals with ASD can be improved with specialised interventions promoting structured, consistent environments combined with strategies to promote social interactions (Howlin, & Rutter, 1987; Ozonoff, & Cathcart, 1998; Jocelyn, Casiro, Beattie, Baw, & Kneisz, 1998). Studies on the core social communication deficits in ASD, such as joint attention (Kasari, Sigman, Mundy, & Yirmiya, 1990; Mundy, Sigman, & Kasari, 1990; Sigman, Mundy, Sherma, & Ungerer, 1986; Mundy, Sigman, Ungerer, & Sherman, 1986), pragmatic communication skills (Prizant & Wetherby, 1987) and the ability to read social meanings (Tager-Flusberg, 1993; Sigman & Kasari, 1995) have raised the possibility of developing tailored treatments targeting such deficits. These deficits are especially important because they are persistent and highly predictive of future outcomes in the social and educational domains and are strongly associated with the severity of behavioural symptoms (Howlin, & Moore, 1997).

In this study, I include a discussion on how ASD has been understood, responses to ASD considered from an empirical standpoint, and explain how dohsa-hou relates to other prevalent responses to ASD. In this chapter, I briefly discuss how we have come to understand ASD and how this understanding fits into the “spectrum” of responses to ASD. I focus on why the history and treatment of ASD, as well as research into ASD, deserve critical attention.

## **Purpose and Research Questions**

The purpose of this study is to better understand the perspectives of the parents of children with ASD on the use of the dohsa-hou method with their children. To do this, I completed in-depth interviews with twenty-one parents from South Korea and Japan whose children with ASD have been experiencing dohsa-hou for at least for one year. I intended to recruit parents from South Korea and Japan because that is where the dohsa-hou method is most commonly used.

The following research questions were used to guide this study:

1. What are parents' perceptions of the behaviours of their child with ASD when their child receives the dohsa-hou intervention and/or when they use dohsa-hou with their child?  
From their perspectives, does taking part in dohsa-hou affect the communication and relational behaviours of children with ASD?
2. What are parents' perceptions of their child's self-awareness when he or she receives dohsa-hou or they use dohsa-hou with their child? Does the child's self-awareness of his/her body image change in any way during and after dohsa-hou (e.g., posture, movement, and bodily self-awareness)?
3. What are parents' perceptions of the facilitators and barriers in schools, homes and communities for their child?
4. What are parents' perceptions of the facilitators and barriers to using dohsa-hou for their child?

In the next section, I will discuss the contemporary definition of ASD.

### **Definition of Autism Spectrum Disorder**

The term ASD refers to neurological disorders of varying clinical presentations that share the core features of persistent impairments in social communication, interaction and restricted and repetitive patterns of behaviour (American Psychiatric Association, 2013; Tidmarsh & Volkmar, 2003). Although ASD also involves multiple impairments in language and social skills, the degree and form of these impairments vary. Consequently, individuals with ASD have different degrees of communication skills affecting, among other things, social-emotional reciprocity, nonverbal communicative behaviours, and building relationships. In addition, individuals with ASD manifest different stereotypical and repetitive behaviours, interests, and activities. These may affect motor movements, sameness in the use of objects, speech routines, and hyper- or hyporeactivity to sensory aspects of the environment. The patterns of deficits in ASD are iterated in the DSM-5 (American Psychiatric Association, 2013). Individuals with ASD have language difficulties that range from near normal expression, to short phrases, to a few single words, to a complete loss of language, to the stereotyped, repetitive, or unusual use of language. The play of individuals with ASD may include excessive lining up of toys or objects, little smiling or social responsiveness, the absence or impairment of imaginative and social play, restricted patterns of interest that are abnormal in intensity or focus, preoccupation with certain objects or subjects, and inflexible adherence to specific routines or rituals. The lack of social communication and interaction in individuals with ASD may include no response to name and/or poor eye contact (Carpenter, Nagell, & Tomasello, 1998).

Researchers have demonstrated the effectiveness of various interventions for ASD, such as physical activities (Lee & Porretta, 2013; Palaestra, 2005; Baranek, 2002), applied behaviour analysis (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Jensen & Sinclair, 2002; Lovaas, 1987), facilitated communication (Biklen, 1990; Biklen & Schubert, 1991), and social stories (Gray,

1994; Gray & Garand, 1993). Although these approaches are widely used around the world, they were developed in Western countries. Other interventions, less widely known, have emerged in Asia. For example, dohsa-ho was developed in Japan in 1973 by Naruse Gosaju (Kumar et al., 2005), and is now used in China, India, Iran, Japan, Malaysia and South Korea (Morisaki, 2005; Kouno, 2005; Yamamoto, 1993; Konno, 1993; Yamanka, 1992; Harizuka, 1986; Konno, 1978).

In the next section, I will discuss how ASD has been understood by professionals, academics and researchers.

### **Understanding Autism Spectrum Disorder**

A review of the history of ASD, including a discussion of how it has been defined and treated, provides information on how the condition has been understood at different times by different disciplines. In this section, I include theories about the causes of ASD.

Theories on autism and the terminology used to discuss it, have changed over the twentieth century. The current terminology (i.e., ‘Autism Spectrum Disorders’ or ASD) has evolved through a process that has been confusing to families, the public, and professionals (Greydanus & Toledo-Pereyra, 2012). In this chapter, I will review the historical theories that have led to the current state of confusion and controversy about ASD. While the thinking of professionals has dominated these theories, the views of individuals with ASD, their families and their advocates have become prominent only recently. The historical review is in four sections: psychopathological theories, psychiatric theories, neurologic theories, and behavioural theories.

#### **Psychopathological Theories**

Psychopathy refers to a mental or personality disorder characterized by mental and emotional suffering. Initially, ASD was seen as a psychopathology, namely childhood schizophrenia. Prior to the first decade of the twentieth century, individuals with ASD were diagnosed with childhood schizophrenia and treated accordingly. However, individuals with ASD

have been considered separately from those with schizophrenia since the beginning of the 20<sup>th</sup> century.

**Eugen Bleuler.** Eugen Bleuler, a Swiss psychiatrist, was the first to use this term ‘autistic’ (Greydanus & Toledo-Pereyra, 2012; U. Frith & C. D. Frith, 2003; U. Frith, 1991) in 1912.

Bleuler presented characteristic symptoms which he considered to be present in schizophrenia and accessory symptoms which might be found in other psychiatric diseases. The main symptoms identified were a loosening of associations, disturbances of affectivity, ambivalence, and autism. Bleuler defined autism as “detaching oneself from outer reality along with a relative or absolute predominance of inner life” (Stotz-Ingenlath, 2000, p. 157). According to Bleuler, in autism, the outer world is only a disturbing factor and has no real value for the person with the condition. He also stated that autistic thinking was marked by experiences of fantasy and daydreams. For Bleuler, the goal of therapy for the person experiencing autism is to repair the broken contact with reality (Stotz- Ingenlath, 2000).

**Carl Gustav Jung.** Psychologist Carl Gustav Jung understood autism as it related to his work on personality types and schizophrenia (Jung, 1921). Jung classified individuals presenting autistic symptoms as being detached from reality or as schizophrenic introverts. In Jung’s theory, the introvert is normally a contemplative individual who enjoys solitude and the inner life of ideas and the imagination. Jung believed abnormal introversion was characteristic of autism and therefore a form of schizophrenia (Jung, 1921).

**Hans Asperger and the Spectrum.** In 1944 Hans Asperger, an Austrian scientist and paediatrician, described ASD as “autistic psychopathy” although his characterization is now termed Asperger Syndrome (Frith, 1991). His work was not widely known outside the German speaking scientific community and only came to greater attention when it was published in English

translation by Lorna Wing (1981).

Asperger described four cases of what he termed the “autistic psychopathy of childhood” in detail. He summarized these and the features of other similar children:

The children were often able, some with extraordinary gifts in mathematics or natural science with creative modes of thinking and objective self-appraisal. But their social and emotional relationships were poor and they were sometimes malicious. Themselves highly sensitive, they lacked feelings for others, had stereotypic behaviours and were clumsy. Language acquisition was not usually delayed, but language use was idiosyncratic. The condition could be recognised in early childhood and was lifelong (Wing, 1981, p. 89).

He identified the following characteristics of the four children he observed: distinct intellectual functioning, learning difficulties, attention problems, problematic behaviour in social situations, and impairment of emotions and instincts (Hippler, & Klicpera, 2003). Asperger’s work identified individuals who had lower intellectual ability and lower language development than individuals with typical development. His participants also were considered as being eccentrics, or obsessives, or as having borderline schizophrenic personality disorders. In this sense, Hans Asperger anticipated a spectrum of behaviour and abilities within autism or what is today referred to as the “autism spectrum” (Wing, 1981).

While he approached children with ASD with a psychopathological view, he came to separate autism from other forms of mental illness through their observations of children with ASD. Asperger viewed four children as having a spectrum of behaviours and functioning skills within a personality disorder, so his perspective seems to be a more psychopathological one. This means that he perceived the behaviours and functional skills of individuals with ASD as an expression of their

disabilities and their difficulties in controlling their emotions and thinking.

### **Psychiatric Theories**

Psychiatry is a medical specialty in the study of mental disorders. It is situated between neurology and psychology (Shorter, 1997). Professionals in the field who specialize in relationships use psychotherapy and other therapeutic techniques in the treatment of individuals with ASD.

**Leo Kanner.** ASD was first termed ‘early infantile autism’ by Kanner (1943). Before Kanner redefined the term as early infantile autism, ASD was understood as childhood schizophrenia (Bleuler, 1911; Jung, 1921). Leo Kanner (1943), an Austrian-American child psychologist, observed eleven children who exhibited a disorder characterized by a profound lack of social engagement, a range of communication problems, and unusual responses to the inanimate environment starting from, or shortly after, their births. Initially, he viewed the children with ASD as feeble-minded or schizophrenic. However, he came to relate autism to schizophrenia as follows, “the combination of extreme autism, obsessiveness, stereotypy, and echolalia brings the total picture into relationship with some of the basic schizophrenic phenomena” (p. 48). He argued that autism was not, as in schizophrenic children or adults, a departure from an initially present relationship; it was not a “withdrawal” from formerly existing participation. He defined ASD as an ‘extreme autistic aloneness’ (p. 49) that disregards, ignores, and shuts out anything that comes to the child from the outside.

Kanner (1943) noted that while some of the children in his study had been diagnosed as schizophrenic at one time or another, and that there were remarkable similarities, the condition differed in many respects from all known instances of childhood schizophrenia. He defined the behaviour of the eleven children he observed as “inborn autistic disturbances of affective contact” (p. 50). After his publication in 1943, the term ‘early infantile autism’ was added to the psychiatric

nomenclature (Kanner, 1971). Ultimately, he came to view ASD as a disabling condition that should be differentiated from other forms of mental illness such as intellectual disability or schizophrenia. Kanner perceived the behaviours of the eleven children he studied as disturbances in relationships, so his perspective seems to have been primarily a psychiatric one.

**Bruno Bettelheim.** Bruno Bettelheim's work on autism was influenced by Freud and a psychoanalytic understanding of the relationship between mother and child (Bettelheim, 1950). Many of Bettelheim's publications dealt with his modifications of psychoanalysis to fit the milieu he created for severely disturbed youth at the Orthogenic School, one of the University of Chicago's laboratory schools. He took Freud's advice into practice, believing that love for the child is the essence of education and everything depends on the intuitive wisdom of his or her teachers (Bettelheim, 1950). Bettelheim's psychoanalytic perspective focused on the emotional and social benefits of play, especially in the context of healthy parent-child relationships, and in particular the mother-child relationship. He believed that successful nursing resulted in the infant's satisfaction and afforded the infant the ability to shape his or her initial experience with the world in ways that met his or her needs. He believed some mothers rejected their nursing role, leaving the child dissatisfied and alienated from the world. In the 1950s and 1960s, Bettelheim developed the term 'refrigerator mother' to describe this so called defensive reaction and published *The Empty Fortress: Infantile Autism and the Birth of the Self* (Bettelheim, 1967) because he believed that insecure parents experienced a need to defend themselves from their unborn child from the very beginning (Bettelheim, 1950). Consequently, Bettelheim claimed that autistic disorder was the result of maternal coldness. In a sense, he identified the parents, in particular the mother, as the cause of their child's autism. It was his belief that, because of their relationship with their child, the parents should not be involved in the child's therapy. Bettelheim blamed the parents for their child's condition. This lack of understanding of the condition and how to approach it left many parents

wrongly feeling they were to blame for their child's condition. One of the first books published to allay the blame that parents, especially mothers, were made to feel about having caused their child's autism through their cold detachment, was written by Park (1968). Park presented a parental perspective. She published *The Siege* about her daughter's life and chronicled, in minute detail, the behaviours of her child with ASD and the family's love and acceptance of their daughter with ASD in her book.

### **Neurological Theories**

Neurology is the medical study of disorders of the nervous system. People with ASD are considered having difficulties to live with a nervous system disorder. That is, ASD is understood that abnormalities in the structure and function of the nervous system have been substantiated in individuals with ASD as causal factors (Brambilla, Harden, diNemi, Perez, Soares, & Barale, 2003).

**Bernard Rimland.** Bernard Rimland, a psychologist and a parent of a child with autism, challenged Bettelheim's theory that the cause of his son's autism was due to either his or his wife's parenting skills and dismissed the idea of the "refrigerator mother". Rimland believed that part of the problem of autism is biochemical (Rimland, 1964). He stressed the plausibility of a biological basis for autism versus the socialization theory of Bettelheim (1950). Researchers in neuroanatomy have noted subtle structural anomalies in the brains of individuals with autism, especially in the cerebellar circuits that permit the normal brain to select, prioritize, and process information effectively (Chez, M., 2008; Amaral, Schumann, & Nordahl, 2008; Pelphrey, Adolphs, & Morris, 2004). When these circuits malfunction, the automatic shifts of attention that make life flow smoothly for normal infants and children are grossly impaired in the child with ASD, so that he or she becomes oblivious to many of the social cues and to the constant stream of cause-and-effect

sequences that give coherence and meaning to normal experience.

### **Behavioural Theories**

Behaviour is the range of actions that constitute the responses of the human body to various stimuli. The stimuli can be either internal or external, and either conscious or subconscious.

Behaviourist clinicians diagnose individuals with ASD, relying on their careful observations of each individual's behaviour. In essence, they observe how individuals respond to the stimuli they receive and then study how to develop behavioural guides to modify 'abnormal' behaviour in individuals with ASD through behavioural instructions and reinforcement.

**Ole Ivar Lavass.** Ole Ivar Lovaas (1967) applied Thorndike's (1905) and Skinner's (1963) work on the principles of reinforcement theory to behavioural problems within clinical psychology. Lovaas argued that:

Behaviour therapy is singular in its concern with definition of variables by their functional properties (p. 109). ... When one views the development of abnormal behaviours from a reinforcement theory framework, emphasis can be placed on deviations in behavioural development. For example, one abnormality might be defined as failure to talk. Similarly, deviations may be viewed as distortions in stimulus functions; for example, a child for whom a smile has no function might be defined in terms of one another, it would be difficult to alter stimulus functions without simultaneously altering behaviours, and vice versa. However, the operations which govern the acquisition of behaviours are different from those which regulate stimulus functions. The use of one of these operations as a therapeutic intervention would require a treatment program of different construction than would the use of the other (p. 112).

He began to apply behaviour analysis to people with autism. At first, Lovaas achieved only

limited success with older children. He refocused his efforts on children under the age of five and shifted the implementation of his program to the child’s own home. Lovaas’s work developed into what is currently called ‘applied behavioral analysis’ (ABA). His work formed the basis for the ABA manuals used in the approach (Wolf, Risley, Johnston, Harris, & Allen, 1967; Lovaas, Koegel, Simmons, & Long, 1973).

**Conclusion**

As the preceding discussion makes clear, different theories on autism and its treatment have fallen in and out of favour. I created a categorization of the historical theories on ASD (shown in Table 1). In each category, the predominant way of thinking about ASD (i.e., psychopathological, psychiatric, biological and behavioural) is identified as a problem of mind, mind and body, body and brain, or behavioral dysfunction.

Table 1

*Categories of Theories*

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Psychopathological theories	Psychiatric theories	Neurological theories	Behavioural theories
▼	▼	▼	▼
Mind	Mind-Body	Body-Brain	Functional

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Researchers have adopted different theories and studied different ways to treat ASD within these different categories. For instance, the psychopathological theories can be located in the “mind” category because their proponents view individuals with ASD having mental or personality disorders. The psychiatric perspective can be categorized in the “mind-brain” category because its proponents view individuals with ASD having behavioural, cognitive and perceptual abnormalities with mental health problems. The biological perspective can be categorized in the “body-brain”

category because its advocates view the differences of individuals with ASD as neurological abnormalities. The behavioural perspective can be categorized in the “functional” category because its advocates view the functional behaviours of individuals with ASD, in daily life, as maladaptive.

The focus of this dissertation is to examine parents’ overall perceptions of dohsa-hou, a treatment method that can be in the Mind-Body category, within a psychiatric perspective on ASD. Researchers in dohsa-hou approach their participants with a theory that people with ASD have communication difficulties and live with difficulties in managing their bodies and minds (Naruse, 1995; Kouno, 2005; Konno, 1993; Toya, 2003). Some researchers (Kumar et al., 2005; Kim et al., 2001) believe that dohsa-hou is one of most effective approaches to redirecting how people with ASD relate to other people and to their own body image and movements. I will discuss more details of this approach, along with other approaches for people with ASD, in Chapter II.

In this study, I proposed to examine parents’ perspectives on the effectiveness of dohsa-hou for their children with ASD. To do this, I interviewed parents who had been using the approach with their children with ASD. The interviews took place in South Korea and Japan because the approach has been used mostly in the two countries, but not in Canada.

In Chapter II, before I examine the use of dohsa-hou with children with ASD, I will review the relevant empirical literature to compare and contrast various theories and perspectives on ASD and their implications for treatment. In addition, I will detail how these perspectives on the cause of ASD have served as theoretical paradigms giving rise to different models of ASD that have, in turn, led to different treatments and attitudes. Then, I will include a more in-depth examination of dohsa-hou and discuss how it fits into these broader perspectives.

## **Chapter II**

### **Understanding and Responding to ASD: A Review of the Literature**

Autism spectrum disorder (ASD) has been a focus of research and scholarship since the 1940s. While there has been extensive research since then, no single conclusive explanation for the etiology of ASD has emerged. Over this period, treatments that claimed to positively affect ASD have been discussed, developed, and ultimately abandoned as new views on etiology and best practices emerged. Understanding and responding to ASD has been mainly the domain of professionals and researchers, although alternative perspectives and responses have been promoted by people with ASD and their families more recently.

#### **The Relevant Empirical Reviews**

In Chapter 1, psychopathological, psychiatric, neurological and behavioural theories were reviewed to comprehend how we have come to understand ASD. With these diverse theories, treatments and approaches for ASD have been developed, used and sometimes abandoned. For individuals with ASD, perspectives, treatments and approaches are related concepts. Theories refer to underlying theoretical constructs that lead to very different treatments and approaches.

Treatments refer to specific methods of medical intervention or behavioral modification intended to ameliorate the condition. Approaches refer to suggestions for coping with ASD or dealing with individuals with ASD, which may be grounded in more than one theory, or derived from practical experience without any clear theoretical justification. I review all three (i.e., theories, treatments and approaches) in order to analyze the different interventions used with people with ASD. The theories discussed in Chapter I and the treatments and approaches for ASD can be categorized into four areas as follows: 1) “mind” which is based on the psychopathological theory of causation about ASD, 2) “mind-brain” which is based on the psychiatric theory, 3) “body-brain”

which is based on the neurological theory, and 4) “functional” which is based on the behavioural theory.

### **Mind**

Typically, mind refers to perception, imagination, memory, emotion, attention, conscious and/or unconscious communication, and unconscious processes of behaviour (Thagard, 2005).

Psychology is the study of mind and behaviour. Professionals working within the psychopathological and psychiatric traditions have considered people with ASD as individuals with mental disorders. For example, between 1940 and 1970, ASD was understood as being one of many illnesses related to schizophrenia. Consequently, in that era, psychologists were viewed as the most appropriate professionals to diagnose and attempt to treat ASD. Since psychologists attempt to understand the role of mental functions in the behaviour of the individual, they explore perception, cognition, attention, emotion, motivation, brain functioning, personality, and behaviour. Today, as a consequence of this history, psychologists have retained a main role in counseling, observing, diagnosing, assessing, and deciding how to treat ASD.

From the 1940s to the 1970s, some researchers called children with ASD ‘autistic schizophrenic children’ in their studies. For example, Bender, Goldschmidt, and Siva (1962) reported that children with ASD presented a defensive reaction characterized as disorganization resulting from the symptoms of schizophrenia. These symptoms included social withdrawal, lack of interest in the environment, lack of emotional expression, inappropriate laughter or crying, depression, oversleeping or insomnia, inability to concentrate and speech difficulties.

**Treatments and approaches associated with the mind category.** While no approaches fall under the mind category, it could be the theoretical basis for the development and implementation of treatments. As discussed above, ASD was considered a mental disorder between 1940s and

1970s. Individuals with ASD were diagnosed as schizophrenic and treated in the same way as patients with schizophrenia. They were hospitalized and received experimental treatments. Based on the theory that drugs and electric shocks could control mental disorders, psychotherapeutic treatments were invented and used.

Although chemical treatments (drugs) and physical shocks (electric shock punishment) had an influence on patients' mental states (Bender, Faretra, & Cobrinik, 1963; Busch & Johnson, 1950; Dhossche & Stanfill, 2004) due to their physical effects, they did not show the intended behavioural changes. That is, the behavioural changes evoked by the chemical treatments and electric shocks did not help people with ASD to live with other people, although researchers observed behavioural changes from the treatments. The chemical and physical shocks treatments, used from the 1940s to 1970s, can be understood as therapeutic treatments in the body and brain category, as well as the functional category, even though the original theory of the treatments was to cure mental disorder.

### **Mind and Body**

The concept of psychiatry lies at the heart of the 'mind and body' category (Schimmel, 2001; Searle, 1994). From this perspective, ASD has been understood from a more holistic view that incorporates all the natural systems, including the physical, psychological, neurological and social systems. From the holistic perspective, systems function as wholes and their functioning cannot be fully understood solely by understanding their separate parts. In other words, mental processes can change physical and behavioural processes, and physical and behavioural processes can affect mental processes.

Baron-Cohen, Leslie and Frith (1986) tested a group of high-functioning children and adolescents with ASD. The subjects were asked to arrange sets of pictures to construct a story. This was an attempt to test one aspect of cognitive functioning as it related to behaviour. They

found that the subjects with ASD were selectively impaired in developing stories, whereas this dissociation was not observed in typically developing 4-year-olds and low-functioning individuals with Down syndrome. Baron-Cohen (1985) described children with ASD as lacking a 'theory of mind'. He explained that children with ASD had difficulties understanding others' emotions and behaviours and that these difficulties caused them to have difficulties communicating with and reacting to other people.

Masters and Houston's (1978) view is that the mind and body interact, each one affecting the other. As an example, drugs can act upon the mind through the body, releasing emotions. In biofeedback (i.e., self-regulation of blood flow, skin temperature, heart rate and brain waves), mind and body can be trained to work together to effect what may be thought of as bodily changes, such as altering blood flow to banish a headache. Alternatively, biofeedback may cause mainly mental changes, such as when brain waves are controlled to produce states of tranquility or creative reverie. From this perspective, the body and the mind are in continuous interaction, affecting each other more or less profoundly and engendering changes of which the person is very often unaware, even though the mind and the body appear to be separate systems (Penfield, 1975; Chan, Sze & Dejian, 2008).

Researchers in neuroscience (Baron-Cohen, 1995; Frith, Morton, & Leslie, 1991; Leslie & Thaiss, 1992; Scholl & Leslie, 2001) ascribe neurological and biological development to physical and cognitive maturation and environmental influences, and posit that delays in these areas are intrinsic to ASD. Leslie and Thaiss (1992) noted that typical children represent mental states with an innate neurological basis, but neurological damage to a system of the brain likely had occurred in children with ASD. Neurological damage in ASD was presumed to be domain specific (Fodor, 1983). However, neurological delay is not the only possible explanation for children with ASD.

Individuals with ASD are more likely to experience substantial psychological stress in meeting others' expectations. Chan, Sze and Dejian (2008) have reported that external pressure combined with deficient self-control, may impede the social and educational functioning, and hence the psychological well-being and quality of life of individuals with ASD. For example, when faced with discordant or unexpected situations, many individuals with ASD tend to respond instantaneously with intense frustration and restless feelings, which can be expressed in terms of challenging behaviours such as yelling, screaming, crying or aggression towards themselves or others (Chan et al., 2008).

Strategies have been developed based on a holistic perspective of ASD in which the body and the brain can affect each other.

**Music therapy.** Music therapy is the utilization of the creative process of art to improve and enhance the physical, mental and emotional wellbeing of individuals of all ages (American Music Therapy Association, 2005). Music therapy is a controlled music experience utilized to facilitate positive change in human behaviour (Evans, 2007). Each session of music therapy is carefully planned, carried out, and evaluated to suit the specific needs of each individual. Music therapy can include any of the following musical activities: listening to music and/or musical creations, playing musical instruments (any instrument can be used), moving to music, and singing (Evans, 2007). As far as ASD is concerned, studies have shown that music therapy has a significant, positive influence when used to treat children with ASD (Boso, Emanuele, Minazzi, Abbamonte, & Politi, 2007; Kim, Wigram, & Gold, 2009). These reserachers suggest that participating in music therapy allows individuals with ASD the opportunity to experience non-threatening stimulation.

***Critique on music therapy.*** Music therapy was introduced as a promising therapy and research has shown positives results (Boso, Emanuele, Minazzi, Abbamonte, & Politi, 2007; Kim,

Wigram, & Gold, 2009). However, the literature and research on the use of music therapy with children with ASD is very limited.

**Art therapy.** Art therapy is based on the belief that the creative process involved in artistic self-expression helps people to resolve conflicts and problems, develop interpersonal skills, manage behaviour, reduce stress, increase self-esteem and self-awareness, and achieve insight (Emery, 2004). In some cases, people with ASD are non-verbal: unable to use speech to communicate at all. In other cases, people with ASD have a hard time processing language and converting it into a conversational format. People with ASD also may have a difficult time reading facial expression and body language. As a result, they may have difficulty comprehending a joke, sarcasm or sincerity. Additionally, it appears that many people with ASD process information visually. For example, Temple Grandin (1995) attributed her extraordinary talents to a reliance on visual information. Her application of her visual information processing abilities to animal science is reported in her book *Thinking in Pictures* (Grandin, 1995). She determined that cattle were terrified in slaughterhouses and pictured what the frightened cattle might be experiencing by putting herself at the animals' eye level. Then, she designed pens and chutes, by applying her "thinking in pictures" approach, to comfort cattle. Her visual processing abilities have led her to better understand these animals and their behaviour, and to better advocate for them. Individuals with ASD can turn that ability to good use in processing memories, recording images, encoding visual information, and expressing ideas through drawing or other artistic media (Emery, 2004).

**Critique of art therapy.** Like music therapy, art therapy was introduced as one of several promising therapies and research (Emery, 2004) has shown positive results. However, the literature and research into art therapy and ASD are limited.

**Facilitated communication.** Facilitated Communication (FC) is a technique originally developed in Australia in 1977 by Rosemary Crossley to assist individuals with physical limitations, such as cerebral palsy, to communicate by typing or pointing to words or letters (Biklen, 1990). The technique was introduced in the United States by Douglas Biklen (1990), a professor of special education at Syracuse University (Jacobson, Mulick, & Schwartz, 1995; Mostert, 2001). Based on his reports that FC allowed individuals, who were previously unable to communicate, to share advanced thoughts and ideas, the approach quickly spread (Norton, 2006). Biklen thought that FC had the potential to provide a means of expressive communication for uncommunicative individuals with ASD (Mostert, 2001). Biklen (1990) believed that while children with ASD understood language, they were unable to express their thoughts due to a type of developmental apraxia that impaired their ability to control voluntary movement. He also emphasized that in using FC individuals with ASD demonstrated their authorship and voluntary intention to write their thoughts. Biklen believed that individuals with ASD would develop self-confidence using FC, demonstrate independent thinking, and gain the ability to express themselves.

FC was initially greeted with enthusiasm in the United States. Public schools invested significant resources in the training and hiring of FC facilitators for ASD students. Families utilizing FC were optimistic about its potential and some saw it as a way for their child to access post-secondary education.

***Critique of FC.*** After a short period, a number of studies appeared that questioned the claims of FC proponents, particularly with respect to the authorship of the thoughts and ideas in the facilitation process (Simpson & Myles, 1995). Eberlin, McConnachie, Ibel and Volpe (1993) conducted a study of twenty-one students with ASD using FC. The students' answers to questions were assessed using FC when they and their facilitators were shown the same pictures and heard the

same questions, when they were shown different pictures, and when the facilitators were auditorally screened from hearing the questions. They concluded that none of the twenty-one subjects in the study demonstrated “unexpected literacy or communicative abilities when tested with the screening procedure, even after twenty hours of training.”

In addition, Simpson, and Myles (1995) examined the efficacy of FC in a study of eighteen students with ASD. The students selected for the study were nonverbal or had extremely limited verbal-expressive abilities. The teachers of the students were given fifteen weeks of training in FC facilitation. The researchers reported that when the teacher knew the answers to the questions presented, the students recorded the correct answer. When students were presented with questions that the teachers did not know the answers to, none of the students answered correctly.

Later, Bomba, O’Donnell, Markowitz, and Holmes (1996) conducted a study of fourteen students with ASD. In their study, none of the students were able to type correct responses to questions after ten weeks of FC training. Finally, Montee, Miltenberger and Wittrock (1995) and Mostert (2001) both concluded from their research that children with ASD were not the authors of the typed responses, but that their FC facilitators were. Norton (2006) noted that parents, teachers and therapists uncritically accepted the claims of FC based on the belief that it was a breakthrough intervention and that it redefined ASD.

**The Feldenkrais method.** The Feldenkrais method is a somatic educational system designed by Moshé Feldenkrais (Feldenkrais, 1981). The Feldenkrais method is designed to improve a person’s movement repertoire, in order to expand and refine self-regulation (i.e., flexibility, relaxation, breathing, etc.) through physical self-awareness, in order to reduce pain or limitations in movement, and promote general well-being (Strauch, 1996). The Feldenkrais Method is often regarded as falling within the field of integrative or complementary medicine (Feldenkrais,

1981).

Feldenkrais believed that health is founded on good physical functioning. He asserted that his method of body/mind exploration improved functioning by making individuals more self-aware. He also believed that flexible bodies helped create flexible minds. The Feldenkrais Method is a form of self-education as opposed to a manipulative therapy. Feldenkrais' approach was essentially experiential, grounded in tools of self-discovery and movement inquiry (Donnellan, Hill, & Leary, 2013).

The Feldenkrais Method contains hundreds of techniques ranging from simple to complex in terms of structure and physical demand. An example of a simple technique is the 'gentle twist'. It is used to help connect movements of the hips, waist, shoulders, spine, ribs, and neck (Feldenkrais, 1981). This technique is divided into two types: Awareness Through Movement (ATM) classes and Functional Integration (FI). In ATM classes, people engage in precise structured movement explorations that involve thinking, sensing, moving and imagining. Each lesson consists of comfortable, easy movements that gradually evolve into movements of greater range and complexity. ATM lessons attempt to make each participant aware of his or her habitual neuromuscular patterns and rigidities and to expand options for choosing new ways of moving while increasing sensitivity and improving efficiency. In FI, a trained practitioner uses his or her hands to guide the movements of a student, who may be sitting, lying or standing. The practitioner uses this "hands-on" technique to help the student experience the connections among various parts of the body. Through touch and movement, the student learns how to eliminate excess effort and thus move more freely and easily.

The Feldenkrais Method focuses on developing one's awareness of movement and provides the student with the ability to improve that movement. The core principle of improving awareness

of one's movements resonates as a useful tool in improving dysfunctions of movement.

***Critique of the Feldenkrais method.*** Researchers have examined the value of this method in reducing stress and anxiety and changing the behaviour of individuals with ASD (Donnellan, Hill, & Leary, 2012). However, research on the effects of the Feldenkrais method on individuals with ASD is scarce. Jain, Janssen, and DeCelle (2004) have noted that current research-based evidence cannot guide clinicians in determining the effectiveness of the Feldenkrais techniques, the length of treatment needed, or the patients for whom it might be most effective.

**Dohsa-hou method.** The dohsa-hou method is a form of psychological rehabilitation developed by Dr. Gosaku Naruse in Japan in the 1960s. Naruse defined dohsa-ho as a “therapeutic activity to promote more appropriate self-activities as a whole including self-control by means of a dohsa (“action”) in an effort to achieve intentional body movements” (Naruse, 1995, p. 4). In its earliest applications, dohsa-hou focused on individuals with cerebral palsy. The researches of Konno and Ohno (Konno, 1978; Konno, & Ohno, 1987) focused on the utilization of the dohsa-hou method to treat children with autism and hyperactivity. Dohsa-hou requires mutual engagement, by the therapist and subject, in movements to promote self-control of emotion, communication, and social interaction. Research on dohsa-hou uses the concept of “joint attention” (Bruner, 1983) to accomplish a triad relationship between the child, the assisting person (e.g., therapist or trained parent), and the task of dohsa-hou (Ogami, 2000). The triad relationship refers to the simultaneous attention of the child and the therapist (i.e., turning attention to the same object at the same time) to form a mutual understanding of each of the tasks of dohsa-hou. Research on joint attention assumes that it is the basic procedure to develop communication and social interaction (Bruner, 1983; Mundy & Crowson, 1997; Whalen & Schreibman, 2003). Joint attention refers to the ability to focus together on people, objects and topics with someone else.

Children normally develop their cognitive, language and social skills through eye contact, gestures, conversations, and joint attention with care givers. However, children with ASD show a joint attention deficit that hinders their development in these areas (Mundy, Sigman, & Kasari, 1990).

Naruse (1966) hypothesized that each person must develop a psychological understanding of the environment around him or herself, including other people. He termed this 'Jiku', which means 'self'. By Jiku he means that a person can develop contacts with his or her environment, only after he or she has established a sense of 'self'. Naruse hypothesized that the basis of 'self' is acquired through the experience of having one's own body set vertically against the force of gravity. Naruse believed that 'self' is the agent for all complex human behaviour. That is, the 'self' is the mainstay of the human being, as 'self' operates the body, and then the body can interact with the environment. Consequently, Naruse sees self-awareness as the foundation for human development.

Toya (2003), in discussing children with ASD, suggested that "if you look at their posture in detail, you will recognize that the children are sometimes not relaxed with dohsa-hou movements. The posture will be targeted and then relaxation tasks and motor action tasks will be applied. It is very important for the therapist to remember that he/she never moves the individual's body actively" (p. 155). Konno (1993) and Morisaki (2005) believed that autism is a developmental disturbance based on brain dysfunction consistent with Kanner's (1943) conceptualization of the disorder as "psychogenic disturbance". Researchers in dohsa-hou understand body image as a psychological construct that relates to the feelings and attitudes each person has about his or her own body. A 'body image', according to dohsa-hou, is created based on the body's physical experiences with muscle tension and relaxation. Through perceiving the

differential sense of muscular activities, a person can recognize their body as their own, and experience an appropriate relationship between mind and body. The psycho-rehabilitative method of dohsa-hou is intended to increase sensitivity to both the physical processes of the body as well as increasing awareness of 'body image'. The application of dohsa-hou to children with autism has demonstrated improvements in the areas of personal interactions and eye contact (Lee, & Cho, 2002; Konno, & Ohno, 1987).

A major goal of the dohsa-hou method is to assist children with autism to establish a sense of 'self' related to body image (Konno, 1993). Dohsa-hou practitioners believe that it is critical to involve the physical (body) in this process of establishing a sense of 'self' (Fujioka, 1992). The approach can be detailed in four stages as follows:

- 1) The objective of the first stage is to assist children to accept the training situation and to relax. To benefit from relaxation training, children need to feel secure and in control of their emotions. It is common for children to experience anxiety when being introduced to body movements by the trainer. The trainer works with the child to control their anxiety by themselves. As the child grows more comfortable, the trainer assists them to move their bodies in a definite direction with the goal that when they enter a more relaxed state they will be able to move their bodies on their own. This stage can take extended periods of time with some children.
- 2) The objective of the second stage is to increase the child's awareness of his or her muscular tension and relaxation and to learn to control his or her muscular tension volitionally. At this stage, the trainer works with the child to increase his or her ability to control muscular tension and relaxation and to enhance awareness of the body and bodily movement. As children learn to focus their attention on their bodies, in a state of

relaxed tension, they begin to experience body movement as a positive experience.

3) The objective of the third stage is to assist children to execute the body movements and to increase their repertoire of movements. The role of the trainer is to work with children to reorganize their body images in positive ways. The desired outcome for a child with autism, for example, is to establish his or her body image in appropriate relationships to “self” and others, evidenced by improved eye contact and emotional stability.

4) The objective of the fourth stage is for children to establish their sense of self-control over both their minds and bodies. At this stage, the trainer teaches the children to move their bodies (arms/legs) as slowly as possible with minimal muscular activity while maintaining their focus on the movement. The desired outcome is that children with autism will experience increased self-control and stability over their minds and bodies (Adapted from Konno, 1993).

Dohsa-hou assists children with autism to develop the fundamentals of communicating with others (Toya, 2003). Those fundamentals include the skills to control one’s own behaviours and to communicate with others. In applying the approach to individuals with ASD, therapists never use behavioural techniques such as reinforcement to reduce challenging behaviour or to increase target behaviours (Toya, 2003). Rather, the therapists assist each individual’s process of striving to achieve motor-action tasks such as sitting, kneeling and standing on one’s feet. In dohsa-hou, therapists never approach challenging behaviour directly. Rather, dohsa-hou therapist supports and helps the individual’s voluntary activity. Toya (2003) suggests that the therapist must continue to pay attention to the individual’s process of striving and adjust his or her own pace to that of the individual.

***Critique of dohsa-hou.*** Qualitative studies of dohsa-hou have reported positive results with individuals with ASD. However, there are some limitations in this research. Firstly, the studies of

dohsa-hou are limited to Asia. Further study in other countries is needed to determine whether there are cultural or other factors are at play. Secondly, the results come from the perspectives of professionals. The perspectives of parents and individuals with ASD are needed for triangulation. Thirdly, experimental studies involving random selection and assignment of children with ASD to experimental and control groups, quantitative measures, and statistical comparisons would strengthen confidence in the efficacy of the method. Lastly, the number of studies on dohsa- hou is insufficient to validate the approach.

### **Body and Brain**

Psychologists studying the connection between the body and the brain, and the resulting behaviour of human beings, have concluded that the body and brain can best be described as being based in the organic and physical world (Bauman & Kemper, 2005; Coleman, Romano, Lapham, & Simon, 1985; Student & Sohmer, 1978). In other words, behaviour is taken to be evidence of brain function. Consequently, many neurologists believe that behaviour is a function of the physical structure of the brain. That is, they believe that abnormal structure and function in the brain contributes to different levels of sensory perception, abnormal behavior, and differences in language development (Bauman & Kemper, 2005).

In the 1980s, several scientists began to look at aspects of brain function as they related to behaviour. Ritvo et al. (1986) noted that there was a loss of Purkinje cells, which are responsible for most of the electrochemical signaling in the cerebella of subjects with ASD. The cerebellum is known to be primarily concerned with the maintenance of bodily balance and motor co-ordination (Bastian & Thomas Thach, 2011) and it is also implicated in several cognitive and affective processes.

A post-mortem neuroanatomical study of subjects with ASD found microscopic

pathology, in the form of increased cell density, in their amygdalas (Bauman & Kemper, 2005; Rapin, & Katzman, 1998). The amygdala receives a great deal of sensory input and responds to somatosensory, visual, auditory, and all types of visceral inputs. Baron-Cohen et al. (2000) thought that the reduced volume of brain cells in the left amygdala of their subjects with ASD was affecting their emotional processing and their identification of emotional information from complex visual stimuli. However, some functional magnetic resonance imaging (fMRI) studies of amygdalas in individuals with ASD have indicated that some subjects had normal amygdala, in terms of structural volume (Baron-Cohen et al., 2000; Filipex, 1999; Nowell, Hackney, Muraki, & Coleman, 1990).

Minderaa et al. (1989) found an elevation of the blood levels of serotonin in individuals with ASD. They argued that serotonin performed a critical role during embryogenesis especially with respect to the maturation of the brain. They argued that it has a modulating effect on a variety of important processes such as sensory perception, learning and memory.

An alternative hypothesis, put forward by Wakefield et al. (1998), claimed a connection between the measles, mumps and rubella vaccine and ASD. They observed that several children who, after a period of apparent normality, lost acquired skills, including communication skills after gastrointestinal symptoms, abdominal pain, diarrhea, bloating, and (in some cases) food intolerance. While their research demonstrated several positive associations of the vaccine and the symptoms, there was no evidence that the vaccines precipitated ASD. Furthermore, an investigation by Brian Deer (April 25, 2004; December 13, 2004) discovered that the lead researcher of the article had multiple undeclared conflicts of interest, had manipulated evidence, and had violated other ethical codes. The paper by Wakefield et al. (1998) was retracted by *The Lancet*, and Wakefield was found guilty by the General Medical Council of England of serious professional misconduct in May 2010 and was struck from the Medical Register. Unfortunately,

the claims in Wakefield et al.'s (1998) research were widely reported (Goldacre, 2008). Thus, vaccination rates dropped sharply in the UK, Ireland and North America (McIntyre & Leask, 2008).

Bailey et al. (1998) suggested that ASD is the manifestation of abnormal brain development and have discovered evidence that several brain regions may be affected. Bailey, Phillips and Rutter (1996), in their empirical review, examined how abnormal brain development is a consequence of both genetic and environmental factors. Research in neurobiology, brain imaging, and neuropsychology point to insights into the possible brain basis of ASD: a) individuals with ASD have specific impairments in processing social and emotional information, and b) core early social impairments, including social orienting, joint attention, responses to the emotional displays of others, and face recognition are common in individuals with ASD (Akshoomoff, Pierce, & Courchesne, 2002; Bailey et al., 1996; Rodier, 2002). The researchers also suggested that ASD is related to dysfunctions in the early development of the brain systems involved in social cognition.

Researchers in animal, human lesion and neuroimaging studies have identified several brain regions that are important for social cognition, including the temporal lobe areas and associated nuclei (i.e., amygdala and hippocampus), the prefrontal cortex, and the inferior parietal cortex (Barbas, 1995; Brothers, Ring, & Kling, 1990; Chaminade, Meltzoff, & Decety, 2002; Bordi & LeDoux, 1994; Williams, Whiten, Suddendorf, & Perrett, 2001). Dawson et al. (2002) suggest six phenotype traits typically impaired in individuals with ASD: a) face processing, which includes the structural encoding of facial features and face movements such as eye gaze, b) social affiliation or sensitivity to social reward, which pertains to the social motivational impairments, c) motor imitation ability, particularly the imitation of body actions, d) memory, specifically those

aspects of memory that are mediated by the amygdala-hippocampus and prefrontal cortex circuits, such as feature binding, e) executive function, especially planning and flexibility, and f) language ability, particularly phonological processing. These researchers suggest that brain damage, in the form of dysfunctional neurological systems, is the underlying cause of ASD. Furthermore, they argue that the brain damage leads to dysfunctions in social interactions (e.g., understanding facial expression and imitation), memory, thinking process and language.

Based on the theory that abnormal brain functioning relates to the abnormal behaviour of individuals with ASD, various approaches using sensory integration therapies, physical movement and manipulation, dietary programs, and drugs have been developed in efforts to repair impaired neurological pathways.

**Sensory integration therapies.** Empirical data from retrospective video studies (Adrien et al., 1992; Baranek, 1999) and clinical evaluations (Gillberg et al., 1990) have indicated that patterns of sensory perception and motor expression in individuals with ASD may differ qualitatively from those with other developmental disorders. Furthermore, unusual sensory perceptual features appear to manifest quite early in the development of children with ASD (i.e., by 9 to 12 months of age). Unusual sensory responses (e.g., hypo- and hyper-responses, preoccupations with sensory features of objects, perceptual distortions and paradoxical responses to sensory stimuli) have been reported in forty two percent to eighty eight percent of older children with ASD (Kientz & Dunn, 1997; Ornitz, Guthrie, & Farley, 1977; Volkmar, Cohen, & Paul, 1986), indicating that these are common concerns in this population (APA, 2013). Sensory processing abilities appear to be uneven and of a fluctuating nature in ASD, such that both hyper- and hypo-responses are evident in the same child. These aberrant sensory reactions are thought to reflect poor sensory integration and/or arousal modulation in the central

nervous system. Children with ASD tend to show these abnormal sensory responses to both social and non-social stimuli and in the absence of known peripheral dysfunctions (e.g., hearing acuity, visual defect).

Sensory and motor treatments often are used as adjuncts to a holistic intervention plan (Baranek, 2002). For example, an occupational therapist might provide therapeutic interventions aimed at improving a child's occupational performance (e.g., play, school functional skills, self-care etc.) within the educational context. The remediation of sensory or motor deficits, as well as other components including cognitive or psychosocial function, also may occur, but only within the larger context of occupational performance problems within the educational setting.

*Critique of sensory integration therapy.* Sensory integration therapy programs are predominantly used in various settings such as schools, clinics and homes. However, professionals and researchers, including physicians, psychologists, and educators have pointed out that sensory integration procedures have not been conclusively demonstrated to be effective (Duntz & Rheingrover, 1981). Some researchers have recommended that sensory integration procedures be applied only in a research context (Arendt, MacLean, & Baumeister, 1988). In response to these critiques, Cermak and Henderson (1990) state that sensory integration procedures are somewhat effective and suggest that researchers need to develop models to examine the effectiveness of sensory integration treatments. Music therapy, art therapy, physiotherapy, the chiropractic approach, and sensory integration treatments are used widely today. However, a review of the literature indicates evidence of efficacy is based primarily on many testimonials, but that empirical evidence is lacking. Researchers should work with clinicians to undertake appropriately designed studies to evaluate the influence of the many variables that need to be considered. Consequently, it is difficult to know if these therapies work to partially remedy ASD or not.

**Diet.** Elder et al. (2006) explored the role of the immune system, genetic susceptibility, and environmental factors such as infections, vaccines, and diet in relation to numerous theoretical models posited to explain the biological basis for ASD. Testimonials from the United States and a number of other countries, in addition to research by Sun, Cade, Fregly, and Privette (1999) have supported the efficacy of the gluten free and casein free diets. The most noteworthy findings in the research are parental and teacher reports of children with ASD, being “cured” of their ASD, acquiring language and showing marked improvement in social relatedness after being placed on gluten and casein restricted diets.

D’Eufemia et al. (1996) and Sun, Cade, Fregly, and Privette (1999) conducted studies of children with ASD to test Dohan’s hypothesis (1966) that schizophrenia is in some way associated with the absorption of gluten and casein. Dohan (1966) formed his hypothesis after studying the dietary habits of societies in New Guinea and other South Pacific islands.

Inhabitants of these areas ate diets free of wheat, rye, barley and oats and reportedly had fewer and less severe cases of schizophrenia than more developed western cultures with diets rich in gluten and casein-containing foods. Dohan asserted that individuals with schizophrenia may have genetic defects that lead to an overload of peptides from milk protein (casein) and/or gluten.

Normally, proteins found in milk and wheat products are metabolized into peptides, and then into amino acids that are absorbed by capillaries in the intestine. High peptide levels may be caused by excess production of peptides in the intestine resulting from abnormal intestinal permeability. D’Eufemia et al. (1996) and Sun et al. (1999) found that b-CM7 ( $\beta$ -casomorphins) from milk could activate opioid receptors and that the activation of opioid receptors may cause secondary dopaminergic stimulation. They assumed that behavioural abnormalities such as ‘explosive motor behaviour’ and repetitive behaviour may represent over-activity of the

dopaminergic system.

***Critique of diet therapies.*** Parents have reported some changes in their children as a result of various dietary regimes. Many believe that a particular diet has had positive effects for their child with ASD. Several studies of various dietary regimes report their effectiveness for individuals with ASD, but rely solely on parents' reports. The results from D'Eufemia et al. (1996) and Sun et al. (1999) demonstrated the relationship between the gluten free and casein free diet and behavioural changes following by neurological effects; however, the results of such studies do not demonstrate a definitive relationship between the diet and ASD. Further research is necessary to develop a better understanding of the possible relationships between diet and ASD.

**Drugs: LSD-25 & UML-491, metrazol, and insulin shock therapy.** Two different categories of drugs have been used with individuals with ASD. One category of drugs has been used to treat ASD as childhood schizophrenia and the other has been used to control behaviours, feelings, and temper levels in individuals with ASD.

There have been a number of reports of the use of psychotherapeutic agents such as metrazol (Cottingham, 1941), d-lysergic acid diethylamide (LSD) and L-methyl-D-Lysergic acid butanolamide bimalate (UML) (Bender, Faretra, & Cobrinik, 1963; Busch & Johnson, 1950; Freedman, Ebin, & Wilson, 1962) and insulin shock therapy (James, Freudenberg, & Tandy, 1937), with varying degrees of success. Heightened perceptual awareness and increased interpersonal rapport were observed when individuals took these drugs. The drugs increased favourable responses in adults, decreased aggressive contact, and made children happier. These drugs have been shown to ameliorate various autonomic nervous system disorders, reduce distorted and hypersensitive reactions to perceptual experiences, reduce disorder in the tone of the vascular bed, and reduce the tendency to autistic withdrawal. Serotonin has been under

consideration as a factor in nervous system disorders (Kety, 1959; Ostfeld, 1960). Bender et al. (1962) reported that several children who had shown extreme aggressive behaviour became quieter, more manageable, and more “normal” in their contacts with other persons. This led them to assume that these medications might tend to “normalize” behaviour rather than subdue or stimulate it. However, the use of UML-491 and LSD-24 caused serious headaches (Vetto, Belzer, Rogers, & Park, 1967).

These therapeutic efforts were meant to modify the retarded, regressed, and disturbed behaviour of children with ASD. The researchers thought that they had succeeded in nudging slow development in all behaviour areas with these treatments, thus enabling children with ASD to achieve more ‘normal’ development. Second, the researchers believed that visceral-vegetative functions, characteristic of schizophrenia, might be overcome. Third, they believed that increased muscle tone and motor patterns might be stimulated in the unstriated muscles of the vascular bed, the respiratory and gastrointestinal systems, as well as in the striated muscles of the motor systems. Fourth, researchers recognized that the perceptual sensitivity and the perceptual distortion of the schizophrenic children might be corrected.

*Critiques of LSD-25 & UML-491, metrazol, and insulin shock therapy.* In conclusion, these therapeutic treatments were focused on autism as a form of psychosis, rather than on autism itself, and the philosophy of this approach was to cure the psychosis (Stafford & Golightly, 1967), as autism was still considered as a form of schizophrenia at the time. This idea likely caused researchers to think of autism as an illness that needed to be cured.

Their results indicated that the drugs they tested enervated children with autism and decreased their inappropriate behaviours. While researchers saw some positive changes with these drugs and thought that they were partially successful, they discontinued their use of the drugs because their efficacy was not supported in further animal tests and because their subjects

experienced confusion and severe headaches (Rodnick, 1942; Stafford & Golightly, 1967).

**Drugs in current use.** Medical practitioners have used a variety of drugs to treat ASD with a focus on managing symptoms (Newsmax, January 2011). There are five major drug categories that are regularly used for symptomatic treatment. The first category is made up of selective serotonin reuptake inhibitors (SSRIs), commonly known as anti-depressants, or drugs that are used to treat anxiety, depression, and obsessive-compulsive disorder (OCD). Some of the Food and Drug Administration (FDA, 2006) approved SSRI drugs used to treat symptoms of ASD, and that can be administered to children above the age of seven, include fluoxetine (Prozac<sup>TM</sup>), fluvoxamine (Luvox<sup>TM</sup>), sertraline (Zoloft<sup>TM</sup>), and clomipramine (Anafranil<sup>TM</sup>). A second category of drugs used to treat ASD is made up of older anti-psychotic drugs like Haloperidol, Chlorpromazine, Thioridazine and Fluphenazine. They are used in the treatment of behavioural disorders with the aim of controlling the intensity of the neurotransmitter dopamine in the brain. These drugs are known to have side effects like sedation, muscle stiffness and abnormal movements. A third category contains anti-psychotic drugs like Risperidone that are utilized in the treatment of aggression and self-injury among children with ASD with 'fewer' side effects reported. The major side effect of Risperidone has been increased appetite and weight gain.

Other antipsychotic drugs used in the treatment of ASD include Zyprexa and Geodon, which are intended to control aggressive behavior and self-injury. Another moderately prescribed drug for controlling hypertensive behaviour is Clonidine. Anti-convulsant drugs, used to control seizures, make up a fourth category of drugs used to combat ASD. Since one in every four individuals with ASD has seizures, the use of anti-convulsants is considered imperative in case management. Drugs such as carbamazepine (Tegretol), lamotrigine (Lamictal), topiramate

(Topamax), and valproic acid (Depakote) are among the most popular anti-convulsants. However, these drugs can only reduce the number of seizures and not eliminate their occurrence completely. Finally, the fifth category contains stimulants that are used to control and treat the tendencies of inattention and hyperactivity. Drugs such as methylphenidate (Ritalin™) are prescribed for attention deficit hyperactivity disorder (ADHD) and in treating similar symptoms in individuals with ASD.

***Critique of drug regimes.*** Studies of the effectiveness of the drugs used to treat ASD have reported positive outcomes but include warnings related to potential side effects. The drug regimes focus on the control of emotion and behaviour for some individuals, but have no impact on the prevention or cure of ASD.

***Chiropractic approach and other manipulative therapies.*** A few studies have reported good symptomatic improvements in the treatment of individuals with ASD using chiropractic approaches and other manipulative therapies (Alcantara, Alcantara, & Alcantara, 2011). Alcantara, Alcantara, and Alcantara (2011) claimed that children with ASD may receive clinical benefit and/or calming relief of concurrent problems as a result of chiropractic intervention. Aguilar, Grostic and Pflieger (2000) carried out a series of chiropractic adjustments on twenty-six children with ASD over nine months. Outcomes from the study were varied, but included improved relaxation and reduced sensory problems in the children. The researchers claimed the following: some children were taken off Ritalin, bladder and bowel control improved, some children started to speak, and eye contact and attention span improved in some children. Other findings included a reduction in hyperactivity and aggressive behaviour. Additionally, five children were able to attend mainstream classes at school for the first time.

***Critique of chiropractic approach.*** Even though researchers in the chiropractic approach

report that it has positive results, the relevant literature and research are limited.

**Summary of body and brain approaches.** Dawson et al. (2002) presumed that progress in genetic science and improved animal models would provide a better understanding of the cognitive and behavioural symptoms and development of ASD and the abnormal development of individuals with ASD. Brain researchers expected that knowledge of the cognitive neuroscience of social and language ability would help define meaningful subcomponents of the complex systems that underlie the impaired social and language behaviour of individuals with ASD (Dawson et al., 2002; Cicchetti, 1984, 1990). Other researchers expected that by studying the impact of early interventions on brain and behavioural functioning in individuals with ASD, they might develop positive interventions designed to have an impact on their social interaction, learning ability, and language ability. A wide range of sensory, nutritional, and pharmacological agents have been tried in attempts to ameliorate ASD symptoms, but it is apparent that there is no sensory therapy, drug, or food regime that produces a marked and specific beneficial effect on the symptoms of ASD (McDougle, Price, & Volkmar, 1994). However, modest symptomatic benefits may be obtained using different sensory therapies, drugs and diets, but there is no evidence that they prevent or cure ASD, at this point in time. Most studies of sensory therapies and diet rely on personal or parental reports to determine effectiveness rather than on empirical, scientific evidence. The personal and parental reports provide important perspectives on the effectiveness of these therapies and diets. However, at the same time, these perspectives might actually reflect placebo effects. Scientific verification with quantitative data regarding the effectiveness of sensory therapies and diet regimes, and possible interactions between these therapeutic approaches, are needed.

### **Functional Behaviour**

The concept of functional behavior refers to behavioural actions, processes and operations in individuals. Professionals with a behavioural perspective focus on the actions, responses and

language processes of individuals with ASD. They have developed methods for modifying how individuals with ASD speak, play, and respond.

The World Health Organization (WHO, 2001) has identified areas of expected dysfunction in children, before age three, with ASD: reciprocal social interaction, communication, and repetitive behaviour. Many children with ASD have a limited play repertoire that can be repetitive and perseverant around certain objects (Spreckley & Boyd, 2009). Some children with ASD present with some functional language, whereas others have little effective communication (Kasari, 2002). Many develop behaviours considered stereotyped in ASD such as hand flapping, walking on tiptoes, or body rocking (Spreckley & Boyd, 2009). Finally, between fifty percent and seventy percent of children with ASD have an intellectual disability (Baird et al., 2006).

Prior to the advent of functional analysis approaches like applied behavioural analysis (ABA), problem behaviour was typically treated by superimposing arbitrary contingencies of reinforcement or punishment (Mace, 1994). By identifying contingencies that currently maintained problem behaviours, relevant consequences were developed to reduce them. The functional analysis methodology emphasized the importance of applied research in contributing to an understanding of the determinants of behaviour and the use of the research results to identify effective treatments that produce generalizable results (Hanley, Iwata, & McCord, 2003).

In psychology, the term functional analysis was used by Skinner (1963) to denote the empirical demonstrations of “cause-and effect relations” between the environment and behaviour. This term has been extended by behaviour analysts and psychologists to describe a wide range of procedures and operations (Haynes & O’Brien, 1990; Iwata, Kahng, Wallace, & Lindberg, 2000). Two key aspects of functional analysis came to the fore in ABA (Hanley et al., 2003): a) the idea that behavioural analysis conveys the effect that behaviour has on the environment or the purpose

of the behaviour for the individual, and b) analysis describes a relation between two variables, specifically between an environmental event and a behaviour, in which one varies given the presence or absence of the other.

Lovaas (1987) claimed that children with ASD who received intensive behavioural treatment (IBT) made significant gains in IQ scores. IBT is an intensive, comprehensive strategy designed for young children with ASD. Interventions run between 18 and 40 hours per week and should begin early. Proponents suggest that it is comprehensive, designed to target a range of skills such as functional communication, play skills, cognitive skills, self-care skills, and problematic behaviour. The goal of IBT is to bring about significant changes in cognitive and language skills, and behaviour on standardised assessments (Tarbox & Najdowski, 2008). ABA evolved out of the work of Lovaas on IBT. ABA involves the application of behaviourist, operant conditioning principles to improve social interactions and to demonstrate the procedures scientifically (Cooper, Heron, & Heward, 1987; Virues-Ortega, 2010; Peters-Scheffer et al., 2011). It is applicable to children in various age groups, with variable functional skills and can be employed in a variety of settings, as the therapist can modify stimulus activities, settings, objects to keep children's interest, and rewards to promote the children's positive results. Koegel, Koegel and Dunlap (1996) and Horner et al. (2005) have used functional assessment information (Hanley et al., 2003) to build positive behavioural supports for children with ASD.

Based on behavioural modification to change the behaviour of individuals with ASD, professionals experimented and developed various approaches, including: shock as a punishment, applied behaviour analysis (ABA), treatment and education of autistic and related communication handicapped children (TEACCH), social stories, The Developmental/Individual Difference/Relationship-based model (DIR)/floortime, picture exchange communication system

(PECS), and pivotal response training (PRT). These approaches have been used for functional changes in behaviour and language but with different foci. While behaviour is the focus of ABA, communication is the focus of social stories, and communication and social interaction are the foci of TEACCH, DIR/floortime, PECS and PRT.

**Shock as a punishment.** The main strategy of this approach was the use of electric shock as a punisher in operant conditioning. Practitioners believed in the efficacy of punishment. Correct responses were positively reinforced, but incorrect responses and/or 5-second periods of inattentive behaviour were followed by “no” and an electric shock. Researchers reported positive changes in children receiving a shock for incorrect or delayed responses. The positive change reported included happiness, improved social behaviour, affection and calmness (Kircher, Pear, & Martin, 1971; Lichstein & Schreibman, 1976).

**Critique of shock as a punishment.** However, the use of electric shocks in the context of ‘punishment’ presented ethical issues (Akerley, 1976; Webster, 1977). Critics noted that shocks administered as punishment might be seen as threatening by a psychologically vulnerable child with autism. Although the results were believed to be successful at the time, the shock/punishment approach is not used today. It is seen as unacceptable by many researchers as it is hurtful/painful. Many researchers argue that using shock as punishment contravenes basic human rights (Amos, 2010; Traniello & Engle, 2010). The researchers note that the use of shock is “aversive” therapy and “torture” as it induces pain, fear, and/or humiliation to control behaviour and induce compliance.

**Applied behavioural analysis (ABA).** This approach was developed by Lovaas in the 1960s. ABA grew out of earlier work on behaviour modification (Heflin & Simpson, 1998). This approach is based on the concept that children with ASD have significant difficulties with

learning being unable to learn through imitation and listening (Spreckley & Boyd, 2009).

According to Cohen (1998), Lovaas originally made use of punishment, but in current practice, this typically does not go beyond a sharp 'no'.

Instead, rewards such as food are used for a correct response. Children each undergo 30 to 40 hours a week of intervention from a team of therapists, family members and helpers. The specific behaviours of the child are targeted rather than any perceived needs arising from the autism being addressed. ABA is an accepted approach and has been reported to be successful for improvements in the areas of language, behaviour, and vocational work (Lovaas, 1967; Grey, Honan, & McClean, 2005; Lecavalier, Leone, & Wiltz, 2006; Tutt, Powell, & Thornton, 2006).

ABA techniques include functional assessment, prompting, reinforcement, shaping and video modeling (Alberto & Troutman, 2006). Functional assessment is a process in which a behaviour or function of a child with ASD is analyzed into its component parts so that those parts can be taught through the use of prompting. The skill to be learned is broken down into small units for easy learning. A prompt is a cue or assistance to encourage the desired response from an individual. Prompting is associated with reinforcements such as food and toys. The goal of ABA is to assist a child with ASD to expand positive changes in his or her behaviour across people, places and situations. The concept of shaping involves gradually modifying the existing behaviour into a desired behaviour. Video modeling is a form of observational learning in which desired behaviours are learned by watching a video demonstration, and then encouraging the child to imitate the behaviour of the model and reinforcing correct imitations.

***Critique of ABA.*** In spite of being among the most efficacious of all the interventions for autism (Cooper et al., 1987; Virues-Ortega, 2010; Peters-Scheffer et al., 2011), ABA remains controversial especially with respect to outcome claims, exclusivity, extensive use, and personnel

(Heflin & Simpson, 1998). There are serious doubts about whether this approach cures ASD as claimed by Lovass (Lovaas, 1987). Critiques of the approach claim it may cause more behavioural issues and does not work for all children with ASD. There are also concerns about the intensity of the program and the stress on the individuals involved in it. Another critique is that ABA is a home-based approach and is difficult to transfer to inclusive classroom settings (Choutka, Doloughty, & Zirkel, 2004; Johnston, 1991; Schoen, 2003). Dawson (2006) argues that behaviourists are not the people who evaluate what recovery from ASD means and how it might be manifested. He also noted that behaviourists train children with ASD in appropriate human behaviours while themselves displaying some of the most maladaptive human behaviours available. ABA in North America is currently funded by many government agencies. In places where it is not funded families pay a fee for the service. The cost of ABA is significant and many families cannot afford it (Gabbard, Gunderson, & Fonagy, 2002).

ABA is a widely used and studied approach with children with ASD. Many of the studies on ABA have demonstrated its effectiveness. Although rooted in behavioural modification, ABA does not utilize early behavioural interventions like shock/punishment. ABA appears to be very effective in dealing with the behaviour of children with ASD. However, more research into the relationship between ABA and ASD is required. For example, research on parental perspectives on ABA may provide more insight into how the approach impacts children's lives.

**Treatment and Education of Autistic and related Communication handicapped Children (TEACCH).** This approach was developed by Schopler, Mesibov, & Hearsey (1995) at the University of North Carolina over a 30 year period. Similar to ABA, TEACCH is basically a behaviourist approach, but with greater flexibility that allows for incidental learning as well as structured teaching. TEACCH focuses on developing appropriate communication skills and

personal autonomy, rather than seeking to reduce problem behaviours. Typically, in the TEACCH method, the spoken word is reinforced by visual materials, such as photographs, rebus symbols or sign language. Reported results show that children with ASD increased eye contact, improved in their daily living skills and decreased their challenging behaviours (Panerai, Ferrante, Caputo, & Impellizzeri, 1998; Panerai, Ferrante, & Zingale, 2002).

***Critique of TEACCH.*** TEACCH aims to improve both social interactions and communication by means of a specially created environment in which the child with autism can function and through a specially adapted teaching approach (Tutt, Powell, & Thornton, 2006). The research supporting TEACCH is limited at this time and more study is required to prove its efficacy (Gresham, Beebe-Frankenberger, & MacMillan, 1999).

**Social stories.** Social stories describe social situations in terms of relevant social cues and appropriate social responses (Swaggart et al., 1995). This allows the individual to ‘see’ relevant social cues. Social stories are individualized for each person and are typically comprised of different but descriptive sentence types. For example, pictures with descriptive words or sentences of the pictures, animated graphics with descriptive words or sentences of each scene. Deciding between using the pictures or the animated graphics is determined by individual preference of the users. There are also various apps that have pre-made social stories which may be customized and used on various devices (Vandermeer, Beamish, Milford & Lang, 2013). The sentence types include: (a) descriptive - information about the setting, subjects and actions, (b) directive - statements about the appropriate behavioural responses, (c) perspective - sentences describing the feelings and reactions of others in targeted situations, (d) control - analogies of similar actions and responses utilizing nonhuman subjects, (e) cooperative – descriptions of how other people will help out in given situations, and (f) affirmative – rules of commonly shared

opinions (Gray, 1994; Gray & Garand, 1993). Social stories should match a child's vocabulary and comprehension level and can be put into booklet format. The child reviews the social stories each day with parents or a therapist. After the use of social stories, children with ASD showed positive changes in social understanding and less inappropriate behaviour (Scattone, Wilczynski, & Edwards, 2002; Ozdemir, 2008).

***Critique of social stories.*** The research literature on social stories indicated that this approach works for communication skills in general, but there is no research examining its relationship to ASD. Social stories are used with children who do read and understand stories (Kokina & Kern, 2010). It requires adequate comprehension to ensure the children understand the social stories. This indicates that if a child has difficulty reading or understanding spoken language, there is little point using a written story as a method of explaining social situations.

**DIR/Floor time.** Dr. Stanley Greenspan (1979), a child psychiatrist, developed a form of play therapy for children with developmental delays and autism. This method is called the "Developmental, Individual-Difference, Relationship-Based model", or "DIR/Floortime". DIR/Floortime is based on the theory that autism is caused by problems with brain processing that affect a child's relationships and senses, among other things. In the floortime method, the actions of the child with ASD are assumed to be purposeful (Greenspan & Wieder, 1997; Wieder & Greenspan, 2003). It is the parent's or caregiver's role to follow the child's lead and help him/her develop social interaction and communication skills. For example, a boy may frequently tap a toy car against the floor. During a DIR/Floortime session, his mother may imitate the tapping action, or put her car in the way of the child's car. This will prompt the child to interact with her. From there, the mother encourages the child to develop more complex play schemes and incorporate words and language into play. This approach is affordable, encourages the voluntary participation

from children, engages them in their natural settings, and uses their favorite toys.

***Critique of floortime.*** Floortime is more child-directed than some teaching methods. Its goal is to increase interactions and communication between children and adults. However, few studies of DIR/Floortime have shown increased communication and social interaction skills for children with ASD (Wieder & Greenspan, 2003; Greenspan & Wieder, 2006; Case-Smith & Arbesman, 2008). The research on floortime is limited and does not provide conclusive evidence of its efficacy with children with ASD (National Research Council, 2011). Additionally, it is not widely used by professionals or parents.

**The picture exchange communication system (PECS).** This approach is a pictorial system that was developed for children with social-communication deficits (Bondy & Frost, 1994). The system uses basic behavioural principles and techniques such as shaping, differential reinforcement, and transfer of stimulus control via delay of reinforcement to teach children functional communication using pictures (black-and-white or color drawings) as the communicative referent. In this method, the child keeps his or her pictures on a PECS board with Velcro. The child learns to use his or her PECS board to create “sentences” by selecting picture cards (e.g., an “I want” card plus a “juice” card). The PECS cards are then given to a communication partner as a request for the desired item. PECS emphasizes teaching a child to initiate requests (for seen and unseen items), respond to questions (e.g., “what do you want?”) and make social comments (e.g., “I see [object]”).

Charlop-Christy, Carpenter, Le, LeBlanc and Kellet (2002) noted that the PECS system has gained widespread use nationally and internationally with children with autism and is appealing for several reasons. First, the system requires few complex motor movements on the part of the speaker and does not require the listener to be familiar with an additional language such as sign language

(Bondy & Frost, 1994). Second, the PECS system has a relatively low cost and is portable and suitable for use in many settings. Third, case reports indicate that the system can be taught relatively rapidly. Bondy and Frost (1994) described the procedures used to train school-based staff in Peru to use the system over a 5-day period. Although no formal data was collected, the school reported that over a 3-month period, approximately 74 children began the PECS training procedures and many children had progressed to the second training phase. The benefits of PECS are that it is a low-cost, portable, easy-to-use system that focuses on promoting meaningful interactions between the child and his or her environment (Bondy & Frost, 1994).

***Critique of PECS.*** Research on PECS found that it is unique among communication systems designed to improve speech, social-communicative behavior, and the stereotypical behaviour associated with ASD (Bondy & Frost, 1994). However, the literature on PECS indicates that while this approach works for communication skills in general, there is insufficient research examining its efficacy in relation to ASD.

**Pivotal response training (PRT).** Pivotal response training (PRT) incorporates a set of specific procedures that may be conceptualized in terms of establishing operations that provide contextual variables that enhance the reinforcing value of stimuli (Michael, 1993). Michael (1993) reports that the procedures incorporated into this training include allowing a significant amount of choice over the nature of the interaction and stimulus materials, reinforcing attempts to respond, and varying tasks frequently. The procedures are more natural because they more closely resemble typical interactions in ongoing and natural activities than unfamiliar activities and settings (Pierce & Schreibman, 1995; Koegel, Koegel, & McNeerney, 2001). Naturalistic or loose training techniques (e.g., loosely controlled contexts, multiple exemplars, and use of preferred objects of the child in the teaching interaction) such as PRT have been used to increase the language skills of children with ASD (Pierce & Schreibman, 1995). These techniques have

also been adapted to increase other complex behaviour, such as social behaviour (Koegel & Frea, 1993), symbolic play (Stahmer, 1995) and dramatic play (Thorp, Stahmer, & Schreibman, 1995).

***Critique of PRT.*** Studies of PRT have shown it to be effective to promote the communication, play and social interaction skills of children with ASD (Baker-Ericzen, Stahmer, & Burns, 2007; Koegel & Frea, 1993; Vismara & Lyons, 2007). However, like ABA, research on PRT does not provide a scientific explanation of the relationship between PRT and ASD.

### **Summary**

Many conceptual frameworks have been developed to explain ASD and to suggest how to support individuals with ASD. In this dissertation, the term conceptual framework is used to categorize the theories and approaches to ASD adopted by professionals and researchers. In Chapter I, I discussed five theories on ASD adopted by professionals and researchers that are based on different conceptual frameworks: psychopathological, psychiatric, neurological, behavioural, and social. In Chapter II, I categorized the four theories as being mind, mind and body, body and brain or functional behaviour and discussed them in detail. A mapping of these theories and the interventions that arise from them is shown in Table 2.

The work of Kanner and Asperger established that ASD was distinct from schizophrenia. The characteristic of schizophrenia that was confused with ASD was psychosis. Psychopathologic theories resulted in the development drugs, such as metrazol, LSD-25 and UML, and insulin shock for schizophrenia. However, these drugs proved to be ineffective with individuals with ASD. It appears that the early medical/psychiatric approach, focused on autism as a psychosis and the utilization of drug therapies to control it, was misguided. While this approach was ineffective with ASD, it contributed to the understanding that ASD is a condition distinct from schizophrenia.

Table 2

*Categorization of Theories and Responses of Professionals and Researchers to ASD*

Perspectives	Categories	Responses
Psychopathologic theory	Mind	
Psychiatric theory	Mind-Body	Music therapy Art therapy Chiropractic approach Facilitated communication Feldenkrais method Dohsa-hou
Neurological theory	Body-Brain	Sensory integration therapies Diet Drugs - Used to treat childhood schizophrenia: Metrazol, LSD-25, UML-491, insulin shock - Used in current practice: anti-depressants, older anti-psychotic drugs, anti-psychotic drugs, anti-convulsants, stimulants
Behavioural theory	Functional	Electric shock ABA TEACCH Social stories Floor time PECS PRT

While psychologists focus on the connection between the mind and the behavior of individuals, neurologists connect the behavior of individuals to brain function. The field of biology has developed a number of technologies to study and understand the connection between brain function and behavior. Neurologists believe that studying the impact of interventions on brain and behavioral functioning in individuals with ASD will contribute to new treatments. Treatments such as sensory integration, nutritional approaches, and pharmacological agents have been tried with individuals with ASD. While there is evidence that these approaches do cause

changes to behavior, there is a lack of evidence that they produce a marked and specific amelioration of the symptoms of ASD. Neuroscientists continue to study and learn about the relationship of the brain to behavior with a focus on ASD. For instance, areas of study such as cognitive neuroscience, with a focus on social and language ability, have the potential to define the subcomponents of the complex systems that underlie the social and language behaviors of individuals with ASD.

While neurologists view the behavior of individuals with ASD as a relationship between brain and body, behavioral psychology focuses on behavior as a learned process. The work of Thorndike (1905) on law of effect theory and Skinner (1963) in the areas of functional-analysis and operant conditioning has led to a number of ASD treatments. In general, these behavioral approaches target specific behaviors and attempt to control or change them through behavioral guidance such as reinforcement and punishment. Currently, Applied Behavioral Analysis or ABA is an example of a behavioural intervention aimed at changing the behavior of pre-school and young children utilizing the principles of behavioral psychology. While still somewhat controversial, ABA and other behavioral approaches are more research based than many of the other interventions utilized and appear to assist children with ASD in learning how to react and connect with people and their environment.

Finally, in scientific studies, there are more holistic understandings of ASD that incorporate the physical, psychological, and biological systems of the individual which is mind-body concept. Approaches within this perspective are grounded in the assumption that systems function as a whole and that functioning cannot be understood by a focus only on specific parts of the whole. In other words, mental processes can change physical/and or behavioral processes, and physical/and or behavioral processes can change mental processes. Approaches focused on the

connection between mind and body are currently viewed as controversial and lacking research based evidence of efficacy. At the same time, there is some research that confirms that the approaches are effective interventions for individuals with ASD.

In this chapter, I have looked into how we have come to understand ASD and how theories, treatments and approaches have evolved over the years. As one holistic application for individuals with ASD, dohsa-hou has been studied primarily in Japan, and to a lesser degree in South Korea, while it is almost unknown in North America. In this study, I document and analyze how parents understand ASD as well as the use of dohsa-hou with their children.

### Chapter III

#### Research Methods

In this study, I proposed to examine the perspectives of parents regarding the effectiveness of dohsa-hou for their children with Autism Spectrum Disorder (ASD). I conducted the study in South Korea and Japan. The research questions in this study were:

1. What are parents' perceptions of the behaviours of their child with ASD when their child receives the dohsa-hou intervention and/or when they use dohsa-hou with their child? From their perspectives, does taking part in dohsa-hou affect the communication and relational behaviours of children with ASD?
2. What are parents' perceptions of their child's self-awareness when he or she receives dohsa-hou or they use dohsa-hou with their child? Does the child's self-awareness of his/her body image change in any way during and after dohsa-hou (e.g., posture, movement, and bodily self-awareness)?
3. What are parents' perceptions of the facilitators and barriers in schools, homes and communities for their child?
4. What are parents' perceptions of the facilitators and barriers to using dohsa-hou for their child?

These four research questions focused on parental perspectives. Since the research questions focused on the parental experiences, thoughts and beliefs in the dohsa-hou method, a qualitative research methodology was appropriate. Qualitative research provided rich and thick description of individual perspectives. Denzin and Lincoln (2011) define qualitative inquiry:

Qualitative research is a situated activity that locates the observer in the world.

Qualitative research consists of a set of interpretive, material practices that

make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (Denzin & Lincoln, 2011, p. 3)

Creswell (2012) examines several characteristics of qualitative research. According to his examination of qualitative research, qualitative researchers: a) often collect data in natural settings, b) collect data themselves and may use an instrument designed by the researcher using open-ended questions, c) typically gather data from interviews, observations, and documents, d) use an inductive-deductive logic process that uses complex reasoning skills throughout the research, e) keep a focus on the participants' perspectives, f) may have changes or shifts of perspectives after the data collection process is begun, and g) convey the backgrounds of the researchers. Qualitative research is a method to “empower individuals to share their stories, hear their voices, and minimize the power relationships that often exist between a researcher and the participants in a study” (Creswell, 2012, p. 48). Data reviews by the participants can be included to de-emphasize this power relationship. Creswell suggests that having the participants review their transcribed interviews, and correct them as they see fit, can help to de-emphasize the power relationship (Creswell, 2012). I expected that parents in Korea and Japan might have different perspectives on ASD and dohsa-hou due to their different cultural backgrounds. However, I found that cultural differences did not cause them to understand ASD and dohsa-hou differently.

“The development of valid and culturally sensitive instruments and effective participant-

centered interventions ultimately depend on the kind of idiographic knowledge only qualitative inquiry yields” (Sandelowski & Barroso, 2007, p. 5). Sandelowski (2000) argued that “qualitative descriptive” studies represent valuable and distinctive data and illuminate participants’ real daily lives.

In this chapter, I outline the methods I used to carry out this study including the identification and recruitment of the participants, data collection and data analysis.

### **Research Design**

I conducted a qualitative descriptive study. “Qualitative descriptive study is the method of choice when straight descriptions of phenomena are desired. Such study is especially useful for researchers wanting to know the who, what, and where of events” (Sandelowski, 2000, p. 334). The data I collected for this study was from interviews with parents, in order to gain their views on how they understood ASD and why they had chosen dohsa-hou as one way to respond to their child’s condition. “Qualitative descriptive designs are typically an eclectic but reasonable and well-considered combination of sampling, and data collection, analysis, and re-presentational techniques” (Sandelowski, 2000, p. 337). As there were relatively few studies of parental understanding of the use of dohsa-hou, it was appropriate for me to fully and carefully describe parents’ perspectives on its use in a systematic way.

### **Research Subjects**

I conducted individual interviews with 21 parents (i.e., eleven parents of children with autism in South Korea and ten parents of children with autism in Japan) to document and analyze the parents’ perspectives on this approach and how it influenced their children. The reason for interviewing in South Korea and Japan was that the approach is mainly used in those two countries.

## Recruitment

First, I obtained ethical permission to carry out this study from the Education, Nursing Research Ethics Board (ENREB) at the University of Manitoba. Once I had received this permission to carry out this study, I contacted various organizations that operated weeklong dohsa-hou camps for children with autism and their families. I sent a letter to the presidents of those organizations (See Appendix A) and recruitment letters (See Appendix B) to ask for their support in recruiting participants for this study. I translated all of the recruitment materials into Japanese and Korean. While I was able to translate from English into Korean myself, I used a free, publicly available online app (via Naver.com) to translate the recruitment materials from Korean into Japanese. The Korean Japanese translator also reviewed these materials to assure that they were coherent and made sense. The letters for the presidents of the organizations indicated the purpose of this research and asked them to forward an advertisement and a recruitment letter to parents of children with autism who had experienced a year or more of dohsa-hou. The two organizations had opened camps allowing access to parents who used the dohsa-hou approach and they were able to help me recruit potential participants. After receiving the recruitment materials, interested parents contacted me directly in order to have any questions answered and to express their interest in taking part in this study. I accepted the first 21 parents who agreed, eleven from South Korea and ten from Japan. Korean parents contacted me directly but I met Japanese parents whom I was told to meet for interviews. I do not know how the Japanese parents were actually selected. I had intended to interview 10 parents from each country. An eleventh Korean parent approached me directly, and I agreed to interview her.

There were some recruitment criteria. The parents' children had to: 1) be 5 to 12 years old, 2) practice dohsa-hou at least twice a week, and 3) have used dohsa-hou continuously for at least for a year. There was no limitation on the severity of ASD in the children recruited.

Ideally, in a qualitative descriptive study, the researcher collects data from participants with the widest possible variation in perspectives. However, I did not know how many individuals were receiving dohsa-hou, nor how many parents might be interested in taking part in this study.

Therefore, I planned on interviewing 14-20 parents in order to gain a variety of perspectives. While it was difficult to know if the participants provided a maximum variation of possible perspectives, data from 21 participants, in an exploratory study, should provide a good initial data set. As suggested by Patton (2002), even single information-rich cases are valuable if the data are collected purposefully. Sandelowski (1995) posits that a sample size of 10 may be considered adequate.

In regard to the interviews in Japan, I translated the invitation letters and recruitment letters into Japanese but conducted the interviews with an interpreter because I do not speak Japanese. However, I can “read” Japanese. Kanji is used in Japanese and it was developed from Chinese characters. Even though China, Korea and Japan have their own languages, Chinese characters are used to communicate and write. The letters in the countries look different because many letters of Chinese characters in the three countries have been simplified. However, the Chinese characters are ideographs so people in all three countries understand what the words and the sentences mean. They might not understand sentences in Chinese characters in other languages completely, but they understand enough to get the meanings of the sentences. For example, if the word ‘學校’ is written down, Chinese, Korean and Japanese individuals will all know that it means a school but they write and sound the word in different ways. Chinese individuals write it as ‘学校’ and read it as “shuexiao [xuéxiào]”, Korean individuals write it as ‘學校’ and read it as “hakgyo [학교]”, and Japanese individuals write it as ‘学校’ and read it as “gakko [がっこう]”. Moreover, there are many similarities between Korean and Japanese. Korean and Japanese are written in the same word

order grammatically. Even though I do not speak in Japanese, I studied the language in university, so I am familiar with the language.

To ensure the quality of interviews in Japan, I recruited a Japanese-English translator. The organization that helped me to recruit the participants in this study in Japan, helped me to find the translator. The organization is based at a Japanese University. Students from abroad attend classes there. The organization had a Japanese-English translator, who was neither Japanese nor Korean. They recommended a Japanese-Korean translator because the organization decided that the Japanese-Korean translator would use more appropriate expressions and had a better understanding of Asian culture. The qualifications of the translator for the interviews in Japan were: 1) possession of a certificate of dohsa-hou to understand the sense of the approach (at least at the level of a trainer), and 2) certification by the Japanese-Language Proficiency Test (at least at the level of N2). The translator for this study met these criteria.

Regarding interviews in South Korea, I translated the invitation letters and recruitment letters into Korean but I did not need an interpreter because I am fluent in Korean and have a certificate in dohsa-hou. The organization in South Korea, and the organization in Japan had access to parents who use the dohsa-hou approach and they were able to help me to recruit potential participants by distributing the recruitment materials.

### **Data Collection**

Once all participants were recruited, the consent letter (See Appendix C) and interview guide (See Appendix D), in either Korean or Japanese, were sent to the participants. Each participant took part in an individual, face-to-face interview in her/his own language in South Korea or Japan. The organization in South Korea and the organization in Japan often offer dohsa-hou camps. Parents with children with disabilities attend the camps to learn and share ideas about the use of dohsa-hou. As participants came from a variety of areas in South Korea and Japan, I

made sure the interview locations were cost efficient and convenient for the participants in this study. Most of Korean parents had their interviews at their homes, but a few of the Korean parents and all Japanese parents were willing to have their interviews at dohsa-hou camps. Although the settings of camps were public, I planned for the interviews to take place in private. The camps were run in buildings with lecture spaces, convention halls and rooms. While children and teachers learned and practiced dohsa-hou, parents of the children had their own meetings and had free time in their rooms. I was able to book rooms for the interviews. Participants picked a time, from their free time, and met me at their private rooms. I confirmed the privacy of the rooms with the organizations in South Korea and Japan.

The main purpose of a qualitative interview is to find out what is “in and on someone else’s mind” and “...allow us to enter into the other person’s perspective” (Patton, 2002, p. 340-341). A one-on-one interview process was chosen for this study in order to gain greater insight into parental perspectives of dohsa-hou. The semi-structured interviews contained a combination of open-ended questions, less structured questions, and probes. A semi-structured format provided a guide for each interview, kept participants focused, and allowed for “individual perspectives and experiences to emerge” (Patton, 2002, p. 283).

The participants were asked open-ended questions about their perceptions of dohsa-hou. Probes were used, as needed, to “seek more clarity about what the person has just said during each of the interviews” (Merriam, 2009, p. 101). Data collection in qualitative descriptive studies typically discovers who, what, and where of experiences with open-ended interviews for broad range of information (Sandelowski, 2000). I referred to a semi-structured interview guide for interviews (See Appendix D).

Once they had expressed their views fully, they were asked probe questions to address

specific issues they might not have addressed while answering the open-ended questions.

Participants were asked to describe: 1) the relations between the approach and behaviours such as listening to others, initiating a communication, interacting with others, and participating in tasks, 2) if the children's self-awareness of their body image and frame changed during and after dohsa-hou (e.g., posture, movement, and bodily self-awareness), 3) if they experienced facilitators or barriers for their child in school, home or community, and 4) if they experienced facilitators or barriers to the use of dohsa-hou with their child. Additionally, the participants were asked to provide contact information to allow for member checking and so they could receive information about the findings of the study. They could change or correct their words after the member checking if they wished to. All participants completed the member checking process. The interviews took approximately 60 minutes each and took place at a mutually agreed upon location. The interpreter who signed up a confidentiality oath attended the interviews and member checking of data for the Japanese parents. She interpreted Japanese to Korean/Korean to Japanese, and her attendance was mentioned to the Japanese parents prior to the interview. I made field notes during the interviews to ensure the details of the process.

A member checking process was completed by every participant. As a member checking strategy, I showed the transcribed interview to each participant electronically. If the participants wanted to add, delete or change the information, they did so. For the member checking process in Korea, I transcribed each interview at my home in Korea, once each interview was completed. The transcribed interviews were sent to the participants electronically. With the participants who responded to me electronically, I completed the member checking process with them. With participants who did not have time to respond electronically, I completed the process by phone. For the member checking process in Japan, I tried to complete the process at the camp because I

thought that there might be less opportunity to talk with the participants once I left the camp.

While participants did not add new data, they did clarify missing or unintelligible words in the transcripts. I transcribed each interview into Korean once each interview was completed. I and the Japanese-Korean translator at the camp met the participants again and the translator helped me to talk with the participants about the transcribed interviews. I used pseudonyms whenever any name (i.e., name of a parent, child, professional, camp, location, or any other direct or indirect form of identification) occurred to protect the confidentiality of the participants.

I also had translation checking, with a Korean-English speaker, to verify the meaning of the interviews transcribed into English. I hired a person who has completed graduate studies in English. All potential identification was removed from the transcripts for the translation checking.

### **Data Management and Confidentiality**

In this study, I used pseudonyms for people and places. The data were securely stored in a Zip driver on a password protected computer file as required by the Tri-Council Policy Statement 2 (Canadian Institute of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). Only I had access to all the data. A Japanese-Korean translator had access to the raw data only from Japan. She signed up on a form to agree to confidentiality of participants (see Appendix E for the Confidentiality Pledge) and attended only the interviews and member checking for the Japanese parents. My thesis advisor, Dr. Zana Lutfiyya had access to the anonymized data in English. My thesis committee members, Dr. Rick Freeze, Dr. Emily Etcheverry, and Mrs. Mary-Ann Updike had access to the anonymized data in the form of summaries and findings from the data in English. Field notes and transcripts were written in Korean. The data were translated in English and anonymized transcripts given to my thesis advisor, Dr. Zana Lutfiyya. Of course, the thesis is

written in English. Any data that are used within my study are masked and all identifiers stripped from the analysis to ensure the anonymity and confidentiality of the participants. Only aggregate data are reported to further ensure the confidentiality of participants. If any comments potentially identified participants, they were not used in the analysis. All participants will receive a copy of a summary of the results of this study. I will keep the summaries and findings until my thesis is complete. Once my thesis is complete, I will delete all the digitally recorded voices of interviews, shred and burn any notes from the interviews, erase all written interviews from my personal computer, and double check to ensure that I have destroyed all the data from the digital voice record and my personal computer. This study will be used primarily for my doctoral dissertation but may be used for future journal article submissions and presentations. I informed all of organizations and participants about this additional use of the data.

### **Research Instrument**

A semi-structured interview protocol aligned with the proposed research questions was used as a guide with each participant. Using a semi-structured interview, the “topics and issues to be covered are specified in advance, in outline form” rather than in writing in exact sequence and wording of questions (Patton, 2002, p.349). The questions in the semi-structured interview helped ensure that “the same basic lines of inquiry are pursued with each person interviewed” but the interviewer “is free to explore, probe, and ask questions that will elucidate and illuminate the particular subject” (Patton, 2002, p.343). The semi-structured interview was used flexibly, and the questions were crafted to avoid leading, multiple, or simple yes-no type questions (Merriam, 2009). See Appendix D for the interview guide.

### **Data Analysis**

I used qualitative content analysis for this study. Sandelowski (2000) states that both

qualitative and quantitative content analysis are appropriate analytic strategies in qualitative descriptive studies. Both require the coding of data and interpretation of its meaning. While counting data instances may be informative, qualitative content analysis provides an opportunity for a deeper level of analysis.

Once the interview data were collected and transcribed, coding and analysis were guided by the study's main research questions. The purpose of coding was to: 1) notice parents' perceptions of relevant changes in their children after the use of dohsa-hou, 2) collect examples of those changes from the parents, and 3) analyze those changes in order to find commonalities, differences, and structures (Seidel & Kelle, 1995). This way of coding was helpful to make sense of and interpret the meaning others have about the world (Creswell, 2007).

Collecting a number of individual stories allows the description of experiences across people. Data analysis is based on developing a theory by piecing together implicit meanings about a category (Charmaz, 2006). I began by reading through each interview transcript with my field notes to get a sense of the data as a whole, making notes about general key themes as well as potential categories and codes. I identified and coded emergent themes and sub-themes. I utilized an open coding of data in order to categorize information in a way that enabled comparison between things in the same category and the development of theoretical concepts (Maxwell, 2012). As findings emerged during this process, specific codes were designated to represent particular categories, perceptions, and concerns (Sandelowski, 2000; Creswell, 2007; Merriam, 2009). To examine the dohsa-hou approach for ASD, I used a triangulation process. I compared and contrasted the findings from my literature review and the parental perspectives.

### **Reflexivity of the Researcher**

I was influenced by the idea of the relationship between the mind and the body as

delineated in dohsa-hou and have used it as a guide in my approach to people with ASD.

Specifically, as an intervention for better communication skills and ultimately better lives.

According to the dohsa-hou approach, the interrelationship between the mind and the body works in a person with ASD as follows: 1) relaxing movements (outer stimulation) helps to experience relaxation and good feeling (positive experience to the outer stimulation), and communication and interacting between a child with ASD and a practitioner constantly happens during dohsa-hou use; 2) continuous questioning about what they are doing together and thinking about the dohsa-hou movements will help the child continuously practice to develop child-self's self-awareness; and 3) through the positive experience, the child will experience to trust a person, learn to build a relationship between the child-self and other person, and learn to accept and understand the surroundings (e.g., people, places, lights, colors, sounds, etc.) that might irritate the child in calmer ways.

I first heard about the positive effects of the dohsa-hou approach at conferences and heard about positive results of dohsa-hou movement from parents of children with ASD and trainers at camps in South Korea and Japan. I was trained in the movements and observed positive results after the use of the movements in the interactive behaviour of children with ASD (Bang, 2005). I hold a certificate in the dohsa-hou approach from Japanese Association of Psychological Rehabilitation. I had experiences with the dohsa-hou method through one-week-camps, seminars, and classes with children with ASD in Japan and South Korea. I became convinced that dohsa-hou might be helpful for children with ASD, and that it has the potential to improve their self-confidence and social skills. However, the study of dohsa-hou has been limited to examine how the approach influences and relates to ASD. I wanted to further study this approach by finding out what parents think about the method. More than others, parents know their children and are most likely to see changes or the absence of changes, in their children as they undergo this treatment. In

addition, their voices may suggest new perspectives that researchers may have missed because of their professional and academic orientations to ASD grounded in psychology, psychiatry, medicine or therapy.

This exploratory study was cross-cultural qualitative research because the interviews with parents were processed in the participants' own languages (i.e., Korean and Japanese). Consequently, the quality of translation and interpretation from English, to Japanese and Korean, and vice versa is important. When the participant and the researcher belong to two different cultures, cultural differences add another layer of complexity in the interpretive process. When the participant and researcher communicate indirectly through an interpreter, this further distances the researcher from the original meaning as intended by the participant and greatly increases the complexity of the interpretive process (Shimpuku & Norr, 2011, p. 1693). The quality of translation and interpretation might be beyond the researcher's control. "When the researcher and the translator are the same person, the quality of translation is influenced by the autobiography of the researcher-translator, the researcher's knowledge of the language and the culture of the people under study, and the researcher's fluency in the language of the write-up (Birbili, 2000)". This was the case of the interviews in South Korea. I am competent to speak in Korean and to understand Korean culture as a Korean researcher. I was able to interpret and translate key themes and Korean cultural sense of some phrases. "When the researcher and the translator are not the same person, the quality of translation is influenced by the competency, the autobiography and the material circumstances of the translator (Birbili, 2000)". This was the case of the interviews in Japan. I hired a Korean translator who is very fluent in Japanese, experienced of translating and who understood Japanese culture well.

As a researcher who is familiar with the dohsa-hou approach, there was a possibility that I might lead participants' intentions during the interviews. I did not step into what the participants

tried to say and I gave them opportunities, as much as possible, to tell their stories. Researchers must account for their biases. Since my previous experience with dohsa-hou might have influenced how I collected and analyzed the data, I used a semi-structured interview guide to help ensure that I asked participants the same questions. Having my advisor read the anonymized transcripts and then comment on my analysis was another safeguard.

### **Risks and Benefits**

As the interviews were based on participants' thoughts and/or critical thinking about the dohsa-hou approach, the interviews did not include more than a minimal risk to participants. As I was interviewing parents of children with autism, there was no potential abuse of the children. If this occurred, I was going to make a report to the appropriate authorities. Potential benefits of taking part in this study might include the chance: 1) to think critically of what they are using for their children, and 2) to understand their child and the approach used with their child.

## **Chapter IV**

### **Results**

In this chapter, I will discuss participants and the differences between South Korea and Japan in the interviews as a result of the data.

### **Participants**

In this chapter, I briefly introduce each of the 21 study participants and describe their family situations. As noted earlier, the 21 participants whom I interviewed were all mothers. Eleven of them were mothers in Korea and ten of them were in Japan. In Korea, I interviewed seven mothers at a dohsa-hou camp and four mothers at their homes. In Japan, I interviewed the ten mothers at a dohsa-hou camp. The range of ages of their children was between four and twelve. Seventeen of the children were boys and four of the children were girls (In Korean, nine children were boys and two were girls, while in Japan, there were eight boys and two girls).

Generally, boys are 4.5 times more likely to have ASD than girls (Autism Speaks, 2016). Although I did not mean to collect data according to the gender ratio with respect to the incidence of ASD that is exactly what happened. After the introduction of the participants, I will present findings related to dohsa-hou and other findings not related dohsa-hou. Only mothers showed an interest in taking part in the interviews. I used pseudonyms for all of the participants.

### **Soojin**

Soojin has a 7-year-old boy who has autism, Woojin. She lives with her husband, Woojin and an older daughter. The family lives in an urban area in South Korea. Woojin was born with jaundice but is otherwise healthy. According to Soojin, Woojin's life skills, language development, social interaction skills, and spatial concepts are delayed. He is also intellectually delayed. Soojin reported that Woojin often clenches his muscles when he is anxious. Woojin likes

salty food. He attends an inclusive classroom in a public school, sitting with an educational assistant who is provided by the school. He started taking additional private classes when he was 4 years old. He has attended speech therapy, sensory integration therapy, music therapy, art therapy and dohsa-hou classes arranged by his family. Soojin learned about dohsa-hou through the internet. She decided to send Woojin to a dohsa-hou class because she expected him to be able to recognize the world and open up to it through the use of dohsa-hou. Through the relaxation and cooperative movements with his dohsa-hou teacher, Soojin thinks that Woojin can develop his self-awareness and that it will trigger his possibilities to learn and live better life. Woojin has been taking a dohsa-hou class for 2 years. In addition, he meets his dohsa-hou teacher once a week for dohsa-hou practice. He has been going to a dohsa-hou camp once a year with his family since 2013.

### **Minji**

Minji has a 12-year-old boy with autism, Seok. She lives with her husband, Seok, one older son and her parents-in-law. The extended family lives in a rural area in Korea. Seok has delayed social skills, cognitive and language development. He attends an inclusive classroom in a public school. He started taking additional private classes since he was 7 years old, including speech therapy, cognitive therapy<sup>1</sup>, psychotherapy<sup>2</sup> and dohsa-hou. His cognitive therapy teacher

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<sup>1</sup> Cognitive therapy is one of the therapeutic approaches within the larger group of cognitive behavioural therapies and was first expounded by Beck in the 1960s. It is based on the cognitive model, which states that thoughts, feelings and behaviour are all connected, and that individuals can move toward overcoming difficulties and meeting their goals by identifying and changing unhelpful or inaccurate thinking, problematic behaviour, and distressing emotional responses (Beck & Haigh, 2014).

<sup>2</sup> Psychotherapy is the use of psychological methods, particularly when based on regular personal interaction, to help a person change and overcome problems in desired ways. There are over a thousand different named psychotherapies, some being minor variations while others based on very different conceptions of psychology, ethics (how to live) or techniques. Most involve one-to-one sessions between client and therapists but some are conducted with groups, including families. (Yalom, & Leszcz, 2005)

introduced dohsa-hou to Minji in 2014. She decided to continue to practice dohsa-hou with Seok because she saw him becoming more physically relaxed and having better concentration and listening skills at both home and at school. Seok has been taking a dohsa-hou class since 2014. He meets his dohsa-hou teacher once a month during school year and two days a week during his vacation. Minji also practices dohsa-hou with her son on daily basis. Since 2014, she attends a dohsa-hou camp once a year with her son.

### **Jin**

Jin has an 8-year-old boy with autism, Jinmoh. She lives with her husband, Jinmoh, a younger son, her parents-in-law and her brother-in-law's family. The families live in a rural area in Korea. Jin described her son as being quiet and having a good personality. Jinmoh does not speak. He used to be very anxious when in an unfamiliar place. He attends a segregated classroom in a public school. He started taking additional private classes when he was 6 years old. He takes speech therapy, cognitive therapy, and dohsa-hou classes. Another mother of a child with autism introduced dohsa-hou to Jin because Jinmoh started hurting himself and Jin was very worried about it a year ago. She decided to take dohsa-hou classes and practices it with Jinmoh every day because he seemed more relaxed and does not hurt himself since they started using dohsa-hou. He has been using dohsa-hou since 2014. He meets his dohsa-hou teacher once a week and Jin practices it with her son on daily basis. She and her son also attend a dohsa-hou camp once a year.

### **Misook**

Misook has a 12-year-old girl with autism, Jooyoung. She lives with her husband and Jooyoung in an urban area in Korea. She described her daughter as very quiet, not motivated to do much and uninterested in most activities. Jooyoung doesn't talk. She goes to a segregated school for students with disabilities. She started taking additional private classes when she was 2 years old. She takes speech therapy, cognitive therapy, psychology therapy, recreation programs for

children with disabilities as well as dohsa-hou class. A mother of a child with autism introduced dohsa-hou to Misook. At the outset, Misook expected her daughter to become motivated to do more in more activities, and to be able to concentrate on the physical movements of dohsa-hou and communicate with her dohsa-hou teacher. She also thought that the dohsa-hou class would be helpful for her daughter's scoliosis. Jooyoung has been using dohsa-hou since 2014. She meets her dohsa-hou teacher for practice of dohsa-hou two days a week and Misook practices dohsa-hou with Jooyoung every day.

### **Miseon**

Miseon has a 12-year-old boy with autism, Minsoo. She lives with her husband and Minsoo in a rural area in Korea. Her son speaks but does not make eye contact and does not seem interested in people. He has a sleep disorder and engages in stereotypic and repetitive behaviour. According to his mother, he is sensitive to sounds and foods. He is very quiet and seems to be very shy. He used to hurt himself when he was anxious but this has decreased since he started using dohsa-hou. He attends an inclusive classroom in a public school. He started taking additional private classes when he was 7 years old. He takes speech therapy, cognitive therapy, recreation programs for children with disabilities, and dohsa-hou classes. Another mother of a child with autism introduced dohsa-hou to Miseon at Minsoo's educational clinic for children with disabilities. Miseon wanted her son to be relaxed and to decrease his self-injurious behaviour. Minsoo started attending a dohsa-hou class and has been using dohsa-hou Since 2014. He currently takes a dohsa-hou class two days a week. Miseon also practices it with her son every day. She attends a monthly dohsa-hou meeting with her son. At the monthly meeting, they meet other parents and children with disabilities who are practicing dohsa-hou and have intensive dohsa-hou practice hours and information sessions at the monthly meeting. Miseon and Minsoo also attend a dohsa-hou camp once a year.

**Suji**

Suji has a 12-year-old boy, Dongho. She lives with the Dongho in an urban area in Korea. She described her son as non-verbal and quiet. Her son has scoliosis and ASD. He seems to get anxious often. Suji said that Dongho's shoulders and neck curved and hardened from the tension that he experienced. He goes to a segregated school for children with disabilities. He started taking additional private classes since he was 5 years old. He takes cognitive therapy, occupational therapy, physiotherapy, and dohsa-hou classes. Another mother of a child with autism introduced dohsa-hou to Suji. She wanted her son to straighten up, to be relaxed in his shoulders and neck, and to move comfortably. Dongho has been practicing dohsa-hou since 2011. He meets his dohsa-hou teacher once a week. Suji wants to practice dohsa-hou with her son but she is too busy to do so due to her own business.

**Soojung**

Soojung has a 9-year-old boy with autism, Insoo. She lives with her husband, Insoo, and one older daughter in an urban area in Korea. She described her son as "one-sided". In Korea this is understood by parents of children with autism to mean that the child has firmly fixed preferences and patterns, rigidly follows them, and has difficulties to communicating or interacting with people. Her son was also described as having delayed cognitive skills and stereotypic behaviour. He attends a segregated classroom in a public school. He started taking additional private classes when he was 4 years old. Soojung was introduced to a dohsa-hou teacher by a mother of a child with a disability when she was looking for a suitable therapist or teacher who could help her son move more comfortably. She liked the fact that her son would constantly communicate during the practice of dohsa-hou and her son seemed to become more relaxed with

it. Insoo has been taking a dohsa-hou class since 2012. He meets his dohsa-hou teacher once a week. He also goes to a dohsa-hou camp once a year with Soojung.

### **Miyoung**

Miyoung has a 12-year-old girl with autism, Injeong. She lives with her husband and Injeong. The family lives in an urban area in Korea. Injeong does not speak but makes sounds. She is very sensitive to changes in places. Although she does not wear glasses, Miyoung reported that her daughter seems to have low vision because her daughter is hesitant and anxious about walking outside and is not interested in going outdoors. Injeong does not go to school. It was a parental decision not to send their daughter to school. Miyoung and her husband tried to send Injeong to school with the school teachers' support, but Injeong showed extreme anxiety and a number of behaviours which she had never shown before. While in class, Injeong would walk around, make noises and not participate. She stays at home and teachers from the school come to the family's place for her education. She started additional private classes since she was 3 years old. She takes speech therapy, cognitive therapy, physiotherapy and dohsa-hou classes. Miyoung learned about dohsa-hou through another mother of a child with disabilities. She wanted her daughter to be able to relax, experience less anxiety and move comfortably because her daughter's hip joint was not flexible. Injeong has been using dohsa-hou since 2013. She meets her dohsa-hou teacher once a week. Miyoung has attended a dohsa-hou camp once a year with her daughter since 2013.

### **Soohyun**

Soohyun has a 10-year-old boy with autism, Jeong. She lives with her husband, Jeong, an older son and a younger daughter in an urban area in Korea. She said her son has stereotypic repetitive behaviour and speaks, but is very shy and quiet in public. Her son has scoliosis. He

attends a segregated school for students with disabilities. He started taking additional classes when he was 3 years old. He takes speech therapy, cognitive therapy, occupational therapy and dohsa-hou classes. A mother of a child with autism recommended practicing dohsa-hou to Soohyun. Soohyun expected the use of dohsa-hou to be helpful for her son's scoliosis and his social interactions. Jeong has been practicing dohsa-hou since 2010. He meets his dohsa-hou teacher once a week and the teacher is the only person who practices dohsa-hou with Soohyun's son.

### **Sukhee**

Sukhee has a 12-year-old boy with autism, Songwoo. She lives with her husband and Songwoo in an urban area in Korea. She described her son as not interacting with people. Her son is delayed in language development. He does not use sentences but can use words to communicate. He attends a segregated classroom in a public school. He started taking additional private classes when he was 5 years old. He takes speech therapy, occupational therapy, physiotherapy and dohsa-hou classes. A mother of a child with autism recommended using dohsa-hou because Sukhee worried about her son's curved and bent over shoulders and neck. With dohsa-hou, Sukhee also expected her son to be better able to concentrate and interact socially with others. Songwoo has been practicing dohsa-hou since 2007. He meets his dohsa-hou teacher once a week. Sukhee and her husband practice dohsa-hou with their son every day. Sukhee attends a dohsa-hou camp once a year with her son.

### **Jaehee**

Jaehee has a 5-year-old boy with autism, Kijeong. She lives with her husband, Kijeong and a younger son in an urban area in Korea. She described Kijeong as quiet most of time but that he makes sounds and wanders around when he gets anxious. Kijeong speaks some words but does not make eye-contact. He attends an inclusive childcare program. A mother of a child with autism

introduced Jaehee to dohsa-hou. With dohsa-hou, Jaehee expects her son to be calm and to learn how to relax. Her son has been using dohsa-hou since 2014. He meets his dohsa-hou teacher once a week for the use of dohsa-hou. Jaehee also practices it with her son 2 to 3 days a week. They do not attend other meetings or dohsa-hou camps.

### **Yumiko**

Yumiko has a 12-year-old boy with autism, Aka. She lives with her husband, Aka and his twin brother who has cerebral palsy. The family lives in an urban area in Japan. Yumiko reported that her son has difficulties with communication and social interaction. He does not accept changes to his schedule. Although others explain an upcoming change in routine, her son nonetheless gets upset. Yumiko thinks that her son does not listen to people and he does not enjoy communicating with people. She thinks that it makes him upset and frustrated when others try to communicate with him. Her son attends a segregated school for students with disabilities. He also goes to a day service <sup>3</sup> for children with autism since he was 2 years old. He takes additional classes, such as TEACCH<sup>4</sup> (Schopler, 1972), life skills and dohsa-hou at the day service. Dohsa-hou was introduced to Yumiko and her son at the day service. Yumiko expected Aka to experience the joy of working together and accomplishment on tasks. Her son has been using dohsa-hou for 10 years. He meets his dohsa-hou teacher two days a week. Yumiko also practices with her son every day. They have attended a dohsa-hou camp once a year since 2005.

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<sup>3</sup> Children with autism/disabilities commonly go to a day service. The day service program offers various educational and the rapeutic classes for children with autism/disabilities.

<sup>4</sup> Treatment and Education of Autistic and Related Communication Handicapped Children program is founded by Dr. Eric Schopler in 1972. Parents who were interviewed mentioned that they learned how to communicate with their child as well as their children learned to communicate with teachers.

**Miko**

Miko has a 6-year-old boy with autism, Taka. She lives with her husband and Taka in an urban area in Japan. She said that her son gets anxious and “zoned out” when he is in a new setting. She said that her son acted like he could not hear because her son did not make eye-contact or respond to her when she spoke with him. Her son attends a segregated classroom in a public school. He has also gone to a day service for children with autism since he was 3 years old. He takes additional classes, such as TEACCH, life skills and dohsa-hou at the day service. Dohsa-hou was introduced to Miko and her son at the day service. Miko wanted her son to be relaxed and to be able to enjoy communicating with others. Taka has been using dohsa-hou since 2012. He meets his dohsa-hou teacher three days a week. Miko and her husband also practice it with their son every day. Miko and Taka attend a monthly dohsa-hou meeting and an annual camp since 2012.

**Yura**

Yura has an 11-year-old boy with autism, Hiro. She lives with her husband, Hiro, and two older daughters in an urban area in Japan. She indicated that her son was not interested in eating before starting to use dohsa-hou. Today, Hiro is obsessed with details of the ways to move and get to places. He is sensitive to the size of objects. For example, he is very scared of a big sized teddy bear. He attends a segregated classroom in a public school. He has also attended a day service for children with autism since he was 3 years old. He takes additional classes, such as music therapy, speech therapy, TEACCH, life skills and dohsa-hou at the day service. Dohsa-hou was introduced to Yura and her son at the day service. Yura wanted her son to become relaxed with the use of dohsa-hou. Hiro has been using dohsa-hou for since 2007. He meets his dohsa-hou teacher once a week for the practice. Yura also practices it with her son every day. They attend a monthly

meeting and an annual dohsa-hou camp.

### **Chiharu**

Chiharu has a 9-year-old boy with autism, Koichi. She lives with her husband and Koichi in an urban area in Japan. She reported that her son is sensitive to foods. Koichi is also sensitive to changes in light, routines, and physical changes of space. He gets anxious easily if there are such changes within the spaces he occupies routinely. He makes sounds and clenches his muscles when he is anxious. He communicates using one or two words at a time. He attends a segregated school. He also has attended a day service for children with autism since he was 3 ½ years old. He takes additional classes such as cognitive therapy, activities in daily life, and dohsa-hou classes at the day service. Dohsa-hou was introduced to Chiharu and her son at the day service. Chiharu wanted her son to be relaxed and better able to enjoy his life. Her son has been using dohsa-hou for 2 years, since 2013. He meets his dohsa-hou teacher two days a week. Chiharu also practices dohsa-hou with her son every day. They attend a monthly meeting and an annual dohsa-hou camp.

### **Rie**

Rie has a 6-year-old boy with autism, Ken. She lives with her husband and Ken in an urban area in Japan. She described her son as nonverbal. Ken did not respond to people at all before he used dohsa-hou. He wandered around when he got anxious. He now attends an inclusive kindergarten. He has also gone to a day service for children with autism since he was 2 years old. He takes additional classes, such as speech therapy, TEACCH and dohsa-hou classes at the day service. Dohsa-hou was introduced to Rie and Ken at the day service. Rie wanted him to enjoy communicating with others and to be more relaxed. He has been using dohsa-hou since 2012. He meets his dohsa-hou teacher once a week. Rie attends at a monthly meeting and an annual dohsa-hou camp with her son.

**Asami**

Asami has a 7-year-old boy with autism, Yuki. She lives with her husband and Yuki in a rural area in Japan. She reported that her son is delayed in language and social interactions. Yuki does not make sentences but he can use words to communicate. He attends a segregated classroom in a public school. He also has gone to a day service for children with autism since he was 3 years old. He takes additional classes, such as TEACCH, living skills, and dohsa-hou classes at the day service. Dohsa-hou was introduced to Asami and her son at the day service. Asami expected her son to develop his social interaction skills through dohsa-hou. Her son, Yuki, has been using dohsa-hou for 5 years. He meets his dohsa-hou teacher three days a week. Asami also practices dohsa-hou with her son every day basis. They attend a monthly meeting and an annual dohsa-hou camp.

**Tomomi**

Tomomi has a 5-year-old boy with autism, Sato. She lives with her husband, Sato, and a younger son, who also has autism. The family lives in an urban area in Japan. Tomomi said that her son is quiet and does not interact with people. According to her, Sato is non-verbal but makes sounds. He does not go to school but has gone to a day service for children with autism since he was 3 years old. He takes additional classes, such as speech therapy, living skills, dohsa-hou, etc., at the day service. Dohsa-hou was introduced to Tomomi and her son at the day service. Tomomi expected her son to be calmer and to develop interaction skills through the practice of dohsa-hou. He has been using dohsa-hou for 2 years, since 2013. He meets his dohsa-hou teacher two days a week. Tomomi also practices dohsa-hou with her son daily basis. Tomomi's whole family attends a monthly meeting and an annual dohsa-hou camp.

**Natsumi**

Natsumi has an 11-year-old girl with autism, Miko. She lives with her husband and Miko in an urban area in Japan. She reported that her daughter was born with low weight. She is quiet and seems not to be interested in people. She has stereotypic behaviours. Miko is preoccupied with books. She likes to touch and smell books, to flip through them, and make the sounds of the pages as they are being flipped. She is sensitive to changes in places and her routine. She attends a segregated classroom in a public school. She also has gone to a day service for children with autism since she was 2 years old. She takes additional classes, such as TEACCH, occupational therapy and dohsa-hou classes at the day service. Dohsa-hou was introduced to Natsumi and her daughter at the day service. Natsumi expected Miko to show her interest and to be active with dohsa-hou training. Miko has been using dohsa-hou for 9 years, since 2004. She meets her dohsa-hou teacher two days a week. Natsumi also practices dohsa-hou with her daughter on a daily basis. She attends a monthly meeting and an annual camp with her daughter.

**Michiko**

Michiko has a 4-year-old boy with autism, Miki. She lives with her husband, Miki, a younger daughter and her parents-in-law in a rural area in Japan. Her parents-in-law take care of her children and a respite worker takes her son to his classes because Michiko and her husband both work. Michiko described her son as nonverbal, and said that he does not respond to people. Miki is afraid of going to new places and eating new foods. Her son does not go to school because he is not old enough. Instead, he has gone to a day service for children with autism since he was 2 years old. He takes classes, such as speech therapy, daily life activities and dohsa-hou classes at the day service. Dohsa-hou was introduced to Michiko and her son at the day service. Michiko expected her son to be able to express himself. Her son has been using dohsa-hou for 1 year. He meets his dohsa-hou teacher two days a week. Michiko attends an annual camp with her son.

**Yume**

Yume has a 9-year-old girl with autism, Mami. She lives with her husband and Mami in an urban area in Japan. She described her daughter as nonverbal and quiet. Mami is sensitive to changes in places and foods. Frequent changes cause her to become anxious and to clench her muscles. She does not like to move or walk outside. She attends a segregated school for students with disabilities. She also has attended a day service for children with autism since she was 3 years old. She takes additional classes, such as TEACCH, speech therapy and dohsa-hou classes at the day service. Dohsa-hou was introduced to Yume and her daughter at the day service. Yume expected her daughter to become calmer than before and to be active. Her daughter has been using dohsa-hou for 6 years, since 2009. She meets her dohsa-hou teacher once a week. Yume and her husband also practice it on a daily basis. Yume attends a monthly meeting and an annual dohsa-hou camp with her daughter.

**Differences between South Korea and Japan**

Parents in Korea and Japan showed some differences when they talked about their child's diagnosis. Many of parents in South Korea were very specific about their child's diagnosis and comorbid conditions, while parents in Japan did not mention any of the other disabilities of their children. For example, some Korean parents mentioned that their children were diagnosed with "autistic developmental disability" and some other parents mentioned that their children were diagnosed with "autistic intellectual disability". The parents who specified their children's diagnoses mentioned that they do not trust doctors' diagnoses, but they had used their child's diagnosis to obtain better educational supports and other supports from the government. Most parents in Korea mentioned that they received a little financial support from the government to send their children to additional programs for their disabilities. However, all parents in Japan

mentioned that they were covered by support from the government for their children to attend classes, no matter their economic state. One of the Korean parents said,

I honestly don't think diagnosis is important. Diagnosis is not united yet in our country. You would get different diagnosis by each doctor and by each hospital. ... The reason why we went for his diagnosis was for his additional education. Once you get diagnosis, you can get additional education for children with disabilities. Children who attend for the additional education do not pay for the tuition. ... There is an activity support program. Do you know about it? I do not think that Canada has it. The program is only for children with the highest level, the first level. Last year? No, it was practised since 2 years ago. To get the support, we went for another diagnosis to get the first level of his disability.

From the perspective of several parents, the purpose of their child's diagnosis was to access a better education and obtain better financial benefits from the government, not to get him or her identified as a person who had a disability.

### **Summary**

I will conclude this section with some observations about the study's participants and their situations. As I mentioned above, only mothers agreed to be interviewed in both Korea and Japan. There were several possible reasons for this. It could be because only mothers, and not fathers, accompanied most children at the camps. It could be that the telling of family stories was the role of mothers. The importance of co-parenting has been reported (Umberson, Pudrovska, & Reczek, 2010), but telling family stories seemed to be predominant role of mothers (Huang, Kellett, & St John, 2012; Sousa, 2011). Although the interviews in this study were focused on dohsa-hou for children with ASD, the participants in this study also expressed their overall perspectives on their

children and their experience of ASD. Consequently, the perspectives of the parents who participated in this study suggested implications on the use of dohsa-hou for children with ASD as well as overall support for children with ASD.

## Chapter V

### Findings related to Dohsa-hou

The focus of this study was on seeking the perspectives of parents on their experiences with dohsa-hou for their children with ASD. Not surprisingly, there were findings related to dohsa-hou. The findings included: 1) involvement of the participants, their children and their families in dohsa-hou, 2) familiarity with dohsa-hou, and 3) parents' beliefs about the effectiveness of dohsa-hou. The parents who took part in this study were familiar with the concepts and practice of dohsa-hou. They believed dohsa-hou was effective for their children. Thus, they were passionate about, and committed to, continuing with dohsa-hou for their children.

#### **Involvement in Dohsa-Hou**

The range of the parents' involvement in dohsa-hou was 1 to 10 years. Six of them had been involved in dohsa-hou for 1 year, four of them had been involved in it for 2 years, three of them had been involved in it for 3 years, one of them had been involved in it for 4 years, and the rest had been involved in it for more than 5 years. Involvement in one approach for a long time (i.e., getting involved for longer than 1 year) showed that the parents who took part in this study believed that the approach was helpful for their children. According to some parents, the approach also was helpful for themselves and their families, and helped them to understand their child and communicate with him or her.

There was an interesting difference in how the parents in Korea and Japan got involved with dohsa-hou. Most of Korean parents in this study said that they were introduced to the approach by other parents who were involved in it, while all the Japanese parents in this study said that a therapist or a practitioner at a day service that their child attended introduced the approach. The possible reasons for the different sources of introduction to the approach could

be found in the interviews of this study. First, it may be because of the different status of dohsa-hou in public programs in education in South Korea and Japan. According to the parents who took part in this study, dohsa-hou was not included in public programs in South Korea, while it was included in public programs in Japan.

According to all Korean parents in this study, there were limited opportunities to get involved in dohsa-hou because of the high cost and the low number of practitioners. Second, the difference may be due to the different public program allowances for children with disabilities in the two countries. In Korea, there were public programs for children with autism with no or low fees; however, dohsa-hou was not considered a public program and, therefore, was not funded. According to most of the Korean parents, families tended to go to public programs to reduce the financial burden. However, the chances of getting involved in public programs were limited due to long waiting lists. Even when there was a chance to get involved in a public program, the Korean parents worried that the quality of the program might not be satisfactory. In either case, waiting to access a public program or dissatisfaction with the program, some parents decided to go to expensive, private programs for their children. Typically, as the parents searched for an appropriate program, they heard about dohsa-hou from other parents.

However, in Japan, all the mothers reported that they were introduced to dohsa-hou in day service programs. In addition to attending school, there were public day service programs for children with autism run by the government. Via the day service, the children with ASD participated in various programs without a financial burden. All Korean parents, in this study, seemed to rely on other parents' experience and recommendations; while most Japanese parents, in this study, seemed to rely on practitioners, when it came to accessing dohsa-hou.

### **Familiarity with Dohsa-hou**

Most parents understood the underlying premise and implications of dohsa-hou, and were familiar with the theory. Most parents used dohsa-hou concepts and phrases to explain the difficulties that their sons and daughters had. They also used dohsa-hou concepts and phrases to explain and describe the intervention itself. Furthermore, they explained actual involvement in using dohsa-hou.

**Dohsa-hou Concepts.** All parents noted that children with ASD experience anxiety and tension in their daily lives. The children's constant anxiety and muscle tension brought them physical and emotional discomfort. They also had barriers understanding the everyday world. As a result of these barriers, children with ASD had difficulties in accepting and interpreting sensory input. This struggle led them to difficulties with social interaction and communication.

With the use of dohsa-hou, all parents came to understand that their children could become more physically and emotionally relaxed. According to the parents, this led to a better sense of the world. Most parents expected that this would lead to a better life with better communication and social interactions for their children. Some parents in this study said that their children with autism had difficulties controlling their emotions and senses. They thought these difficulties with controlling their emotions and senses caused the children's physical stiffness, unbalanced physical growth, behavioural difficulties and difficult interaction with people. The parents believed that the use and practise of dohsa-hou helped children with ASD to relax from the physical discomfort and finally to have better quality of life. One parent's comment typified what many reported. As she said,

Dohsa-hou came from clinical psychology. It is a way to impact on mind through body. Umm... Physically... In cases of children with autism, they have

unbalanced postures and movements and twisted body. It is quite often shown in children with autism. In those physical parts, the use of dohsa-hou helps to relax and make proper postures and movements. Then, it helps to behave calmly. I think the use of dohsa-hou works on body and mind both. ... When a teacher practises the use of dohsa-hou with my son, I can see that he is relaxed on his waist and back and he can move the parts smoothly. His waist and back are usually quite tensed. But after the use of dohsa-hou, he is relaxed and moves his previously tensed body parts smoothly. There is no tension. So he would feel the relaxation. His mind also would be relaxed and be able to listen carefully. Then interacting with others would also be better. ... For a short term, we expected his postures would be relaxed and properly set. My husband and I see that our son is now relaxed on his tensed and uncomfortable body parts with the use of dohsa-hou. However, we expect more advances on his mind (in his thinking). Like communication? Feeling joy of interacting with people? In a long term, the use of dohsa-hou would help him to experience social interacting and he would know what it feels like to communicate with others. He would know communication and social interaction is joyful. Once he understands how joyful and how important relationship with other people is, he would be able to understand his situations and enjoy his life.

According to all parents who took part in this study, dohsa-hou helped their children to relax from physical tension and emotional anxiety and to develop social interaction skills.

Some of the parents said that dohsa-hou offered a way of understanding their child and communicating with their child. They described their children “zoning out” or “locking

themselves” in their own world. According to the parents, their children with ASD were able to focus on inputs and learn how to be out of “their world” to communicate or interact with others through the use of dohsa-hou. One parent said,

My kid zones out often. When I sit with him, his eyes are often on other things. Then, I realize that he is in his own world. When he is in his own world, he doesn't know what we are talking about even though he was talking with me perfectly fine right before. ... Before I knew that he could have a longer concentrating ability, I punished him a lot. I didn't understand why he didn't understand something that he did just before. After I realized that his concentrating ability would get better with the use of dohsa-hou, I feel that he is now able to learn something and expect a lot from it.

This mother believed that her son sometimes stayed in his own world. The mother mentioned that she expected her son to come out from his own world and to develop a better ability to concentrate. Dohsa-hou seemed to be a helpful approach for her son that enabled him to come out of ‘his own world’, to be able to communicate with other people and, for her to better understand her son.

No one mentioned that dohsa-hou or any other approach would cure autism. Some parents noted that there was no perfect approach or therapy to treat a child with ASD but rather that dohsa-hou was one of several positive methodologies that could be utilized. One parent said, “One thing does not change everything. But, it can be a part of changing things.” In addition, another parent stated,

It or any other approach does not show the big difference on my child.

Nevertheless, I think it this way. When you plant bean sprouts, you water beans

and the water passes through the beans. Even though the beans are not in the water, they grow. We are in this case. Having lots of education and meeting lots of people don't show or shape a thing, but it works like watering bean sprouts. I think dohsa-hou is one of many therapeutic educations. For example, there are 10 subjects to learn in an elementary school. There is no one solid approach to treat a child.

Most parents who took part in this study believed that there were many good approaches for children with ASD and that dohsa-hou was one of them.

Most parents in this study accepted the premises of dohsa-hou. They believed that people with ASD had anxiety and physical tension. They believed that difficulties from autism started with a mental state that affected the individual's physical state. According to them, people with autism are able to achieve mental relaxation if they are helped break physical patterns such as muscle tension or physical discomfort. They thought breaking those patterns through dohsa-hou was achieved through the physical support that came with the touching, positioning and verbal support incorporated into the method. Some parents thought that the use of dohsa-hou by parents seemed to be very helpful for the relaxation and better body posture and movement of their children. The practice of dohsa-hou helped parents to better understand what their children experience. One parent said,

Children with autism have low senses. It is more difficult on peripheral nerves. Even though it is his hand, his recognition of his body is low. Therefore, he does not know how to use it. Because there is a problem in his brain, he does not know how to use his hand. However, if we constantly use our body in a wrong way, the wrong body postures set in uncomfortable ways. Moreover, they have lacked feeling on their body so the use of dohsa-hou helps them in

the opposite way to understand what they do not understand. Originally, the brain orders to move but it does not happen in a child with autism. Therefore, using dohsa-hou, you stimulate the child's brain in the opposite way. You can help them feel and understand their arm's movement.

This mother explained that dohsa-hou was helpful with easy to follow steps, a gentle approach, and a way of thinking that helped her understand her child with ASD.

According to most parents in this study, breaking unhelpful physical patterns with dohsa-hou also contained a communicative intent. The parents understood that by using dohsa-hou, children with autism could experience and learn how communication between two people works. In a dohsa-hou practice session, a dohsa-hou practitioner tries to communicate with verbal and physical directions. During this process, the child concentrates on the movements and the practitioner's directions. All parents believed that physical contact helped to grab their child's attention because children with autism were sensitive to those physical contacts. Although the initial use of dohsa-hou might result in unpleasant feelings for their children with autism, the parents thought that by focusing on these movements, their children learned how to relax, move comfortably, and communicate better.

**Actual involvement in using dohsa-hou.** The children of this study practiced dohsa-hou in different ways: (a) some of them attended only dohsa-hou classes, (b) others attended classes, meetings and camps, and (c) some also practiced at home with their mother or both parents. In a class, a dohsa-hou practitioner used dohsa-hou with a child on a one-on-one basis. There were two types of monthly meetings. At one, the parents met with other parents and children to share their experiences and to practice dohsa-hou together. The second meeting was with a supervisor who

monitored the parental usage of dohsa-hou and provided ideas on how to practice dohsa-hou more effectively with their children. Finally, the practitioners, parents and children stayed at week-long camps each year to take part in an intensive program. There were two types of family practice: (a) mothers or both parents practiced dohsa-hou with their child on a daily basis as an activity in and of itself, and (b) mothers or both parents used dohsa-hou with their child in specific situations to help calm them and be better able to engage them in other activities.

As noted above, most parents in this study were familiar with dohsa-hou concepts and relied on them to help understand their children with ASD. They believed that children with ASD experienced less anxiety and tension with the use of dohsa-hou and that it led to better life for their children in their communities. Most parents were passionate about their belief in the effectiveness of dohsa-hou, and this allowed them to use and practice the approach for their children. Some of the parents had been involved in the use and practice of dohsa-hou for many years. Eleven of the 21 parents had been involved in it for over 3 years and the rest had been involved in it for 1 or 2 years.

According to the parents who took part in this study, a one-hour class cost approximately C\$30 in South Korea while the cost was subsidized in Japan. Eight of the 21 parents' children had been taking one class weekly, 10 children had been taking two classes weekly, and the rest had been taking three classes. Eleven of the 21 parents had been attending monthly meetings that cost approximately C\$50 – 100 per meeting in South Korea. The cost of attending monthly meetings was subsidized in Japan. All the parents indicated that they had been going to yearly camps. One week of the camp cost C\$500 in South Korea, and again, the cost was subsidized in Japan. Despite the cost, half of the parents had used (and paid for) dohsa-hou for over 3 years, while two parents had been involved for 9 and 10 years respectively. Fourteen of the 21 parents stated that they

actively practiced dohsa-hou with their children. Although it cost a lot to attend the classes, meetings and camps, all the parents did not seem to mind spending their money to go. They reported that their time was the bigger constraint. Their passionate involvement in dohsa-hou demonstrated that parents understood that their children with ASD needed lifelong support as it was not a condition that could be cured.

### **Parents' Beliefs on the Effectiveness of Dohsa-hou**

Most parents believed that the use of dohsa-hou was effective for their children, while a few parents were not sure about the effectiveness of the approach. In general, they believed that there was a relationship between physical relaxation and emotional relaxation. According to them, through the practice of dohsa-hou, the physical and emotional relaxation resulted in mental and cognitive development evidenced by better communication, feelings of joy, and better interactions with people. They thought this allowed their children to better enjoy and appreciate their lives. They also used it as a coping mechanism, in new or stressful situations, to improve their children's communication and concentration. They believed that it helped their children to manage situations such as travel, bedtime and dental appointments. As importantly, they believed that their children liked doing it. Thus, parents were passionate about dohsa-hou and readily used it.

**Relaxation.** According to most parents, their children with ASD were sensitive to changes in their daily life, got frustrated, and finally developed anxiety with a high level of muscular tension. People live in a world of change. These changes can be related to sounds, times, schedules, people, places, items and anything else. For example, one parent said,

We sometimes go out for dinner. It was still bright outside when we walked into a restaurant but it got dark when we were leaving the restaurant after

dinner. He yelled at us that it was different and did not step out of the restaurant.

We thought about why he was reacting that way and kept thinking about it.

After we tried to figure out the reason of his reaction, we realized that it was because the darkness might change the image of the landscape of the outside to him. He dangled from his dad or me and did not stand on the ground.

This example showed how stressful the lives of children with ASD and their families might be.

According to the all parents in this study, the general anxiety level of their children decreased once the children began to do dohsa-hou. Their children learned to relax and move comfortably during the dohsa-hou sessions. Most parents mentioned that the relation was both physical and emotional. They believed that the physical relaxation brought on emotional relaxation. As the children learned how to relax and move comfortably, they became better able to manage their emotions. Some parents noted that their children were able to relax themselves with a simple reminder to use dohsa-hou when they encountered situations that make them anxious. This simple action allowed them to accept the bigger world around them and be able to do more things. As one parent said:

He is very sensitive. The effectiveness of relaxation helps him reduce his anxiety. ... For example, he is able to ease on his muscles to relax. In my child's case, he has high level of tension in his hand muscles. At that moment, the use of dohsa-hou helps him calm. For example, once he knows how to relax his muscles, he can ease on his hands and relax with saying 'ease on your hands and relax.' Once he practises relaxing his shoulders, he can relax his shoulders when he is told to do so. To help him relax his shoulders, he bends his back backwards. He tends to bend his shoulders forward so his shoulders get tensed. Once he eases on his shoulders, he feels comfortable and relaxed at the same

time. Then, his anxiety goes down. He can get calmed and relaxed. I think the use of dohsa-hou is very effective to calm him down. It is certainly helpful for relaxing physically and emotionally. He is able to relax by verbal direction or physical support. ... I believe that the practices of dohsa-hou with various teachers helped him live better in daily life. Of course, he fears the sound of the machine at the dental clinic so he would need to practise to get used to it but... Walking into a dental clinic, lying down on a chair, opening his mouth for his dentist, letting the dentist touch him and being calm through the check-up are all possible through the use of dohsa-hou. That is what I think.

According to this mother, her son could reduce his anxiety, go to more places, and do more things with dohsa-hou practice.

**Self-awareness.** Most parents noted that their children developed a better understanding of their body movements and themselves through the use of dohsa-hou. As a result, their children seemed to have better self-recognition and to develop self-awareness. The parents mentioned some examples to demonstrate why they believed that their children developed and increased their self-awareness. Most of the parents mentioned that their children could point to and move a body part as instructed. One parents said,

With a better posture... Even when he watches TV... He is zoned out when he watches TV. I tell him “your posture!” and then he says “yes!” and corrects his posture. He seems to think “Ah! I lost my posture. I need to correct it.” The moment of zoning out is reduced with his self-correction on his posture. When he loses his posture, he bites all his ten fingers. He has lost most of his fingernails. When he loses his posture, it happens more often. However, when

he keeps good posture, he does not have time to bite his fingers. Therefore, I think it is effective. I cannot explain its effectiveness professionally, but when he corrects his posture and keeps it, he does not go zoning out. Once he does not go zoning out, he does not bite his fingernails.

As shown above, the parents believed that their children showed: (a) less 'spacing out', (b) less inappropriate behaviours such as 'finger chewing', and (c) less angry. They thought their children were better able to manage their anger and desist from hurting themselves. Finally, they thought their children were better at caring about and understanding their surroundings, as the results of having developed better self-awareness since stating the use of dohsa-hou.

**Communication and related behaviours.** All parents believed that using dohsa-hou helped their children improve their communication skills. They defined communication broadly. For instance, some parents indicated that the action of expressing their intentions (e.g., telling and/or showing which body parts or movements they wanted to focus on during the practice of dohsa-hou), making eye contact and listening to people could be considered communication. Some parents noted that there were constant interactions and communications between their children and their dohsa-hou practitioners during the practice of dohsa-hou. They noted that their children recognized and learned the process of communication from the constant experience of dohsa-hou. They also said that interactions occurred and were learned when their children focused on, and cooperated in, the mutual movements during the use of the approach. One parent said,

I think using dohsa-hou can be helpful for my child to communicate with the teacher. It [communicating with other person] is actually very difficult for my child. Socially interaction is still difficult for him but he can interact with others,

watches others and cooperates with what others do. And... he listens! He still does not make eye contact with others. He looks down when he talks with another person. However, he listens. And... he keeps up with other person. When he practices dohsa-hou, he follows a teacher's directions. I think he communicates with his teacher during the practice of dohsa-hou. I believe this is his change in communication and social interaction. Keeping up with other person. Listening to the person. Don't you think these are good? For example, my son did not respond at all to another person's words like "could you bring that?" before. Now he does. When I see it, I think 'ah! He is listening!'

Some parents pointed out that one of advantages of dohsa-hou was that verbal communication skills were not necessary. Some of children with ASD had limited to very limited verbal communication skills. According to some of the mothers, communications and interactions happened during the dohsa-hou practice with simple body movement directions. One mother said,

The advantage of dohsa-hou is that you can communicate no matter where your language level is. You can communicate through physical movement. When a teacher is trying to use dohsa-hou with a student, the student would get to catch what the teacher wants to do during the movements. Once the student is able to understand what the teacher is trying to do, the student will try to be on the teacher's pace and follow the directions. During the process, communication occurs between the teacher and the student. Isn't this great? You can tell "hold this part" only with touching. You can show your intention through physical movements. Verbal explanation is not necessary. From that process, you can sense of what other person is trying to do and what you would need to do. I think

it develops social interaction. My child is having difficulties on language so the point is beneficial for him. Anyway, dohsa-hou is one way of communication between a person and a person. There are many ways to communicate and this is one of them. Speaking is not the only way to communicate. Writing is also communicating and physical interacting like dohsa-hou is communicating. In that point, I think dohsa-hou is effective. Especially, even though a child with autism can speak, the child might just say only what s/he is interested in and act his own way. It is one-sided. In the situation, interacting does not happen so communication is not occurring. Being able to speak does not mean being able to interact with another person. From the point, I believe dohsa-hou is effective. Dohsa-hou gives my child an opportunity to experience what is social interacting and communication.

Since dohsa-hou could be practiced with simple physical directions, it led children with ASD to participate easily in dohsa-hou practice.

**Joyful activity.** Some parents mentioned that they had wanted their children to get involved in a program that they would enjoy. According to them, their children were happy to see their dohsa-hou practitioners for their dohsa-hou sessions. The parents noted that their children had positive experiences, relaxed during the use of dohsa-hou, and seemed to be happy with the use of dohsa- hou. They said they were satisfied that they were doing something positive together with their children. One parent indicated words that she imagined her son might say if he was verbal. According to the mother, her son was nonverbal but she could sense her son's happiness to meet his dohsa-hou practitioner and her son's joy during the practice of it. She indicated that she could get a sense of her son's thinking, "Mom, I feel smooth movements on my arm since I

used dohsa- hou. I feel smooth movements on my leg.” She felt he liked dohsa-hou because he sits and waits for his dohsa-hou practitioner and indicates where to practise dohsa-hou. This mother used ‘smooth movements’ to interpret her son’s behavior to mean that dohsa-hou made him feel relaxed and good.

As another parent said,

I thought that my child would have a positive experience during the use of dohsa-hou. He would do more possible things than impossible things. ... I wanted to share a pleasant feeling with him from ‘accomplishing something together’. It is not like... just I feel accomplished something and my child feels ‘pew, it’s finally done.’ I want him to feel ‘ah! This is what mom wants to me to do with her! This is it! I did it! I did what you expected, mom!’ ... And, the movements of dohsa-hou are easy to follow for him. If he did not experience the ‘slow’ movements and positive feedbacks, he would have only negative experiences with saying ‘Stop! Stop!’

Some parents noted that dohsa-hou had a positive impact for both their children and themselves. The parents wanted an intervention that their children would like. They were satisfied to see their children took part in something they enjoyed. The parents were willing to become engaged in dohsa-hou as it helped their children have a better life. According to them, they tended to choose a joyful approach for their children, as there was no ‘best’ or ‘perfect’ approach. One of the parents said, “There is no one perfect education or support. What type of parents in this world would want to put their child in a class that the child does not like or want to do? I want my child to have something he likes to do and feels good about it.” The parents were clear that, through dohsa-hou, they were far better able to understand and communicate with their children. They

reported that they could also share their feelings while doing dohsa-hou. One of the parents said,

I did not want any of unpleasant or unhappy situations that made my child cry or feel angry. In different situations, he did not understand what other person is saying. It resulted in a situation making the person and my child angry or upset although he did not mean to. ... I kept asking myself, 'Could he have a better life? Could my child stay away from this kind of unpleasant situations in his life?' I thought it would be nice if he would experience any kind of pleasant situations. It did not need to be a special thing. If he encounters the situation that other people say, "you are amazing!" to him, he would feel good or happy rather than putting him to feel bad or upset. I started from there. I made many mistakes and failed a lot during the use of dohsa-hou with him, but I got responses from him and I came to understand him more. I tell other people about what I have found about my child. I think it helps others understand him better and it helps him communicate better with others. I think that he came to have pleasant times with me and other people, more than before. I believe he is now having a more pleasant life. Although it took a long time to understand him and to find better ways to communicate with him, it is the reality that one thing does not change everything right away.

**Using dohsa-hou in everyday life.** While the children were engaged in dohsa-hou in a variety of settings with practitioners and parents, the parents also used dohsa-hou to help their children cope with daily activities that were stressful. Eleven of the mothers said that they practiced dohsa-hou home with their sons and daughters and 3 said that both parents practiced dohsa-hou home with their sons and daughters.

The parents using dohsa-hou in their daily lives explained that they used it to help manage situations their sons and daughters found stressful. As examples, they used it before going to bed, on trips, on commutes, in new situations, and in situations that caused their child to feel anxious. One parent said, “I practice dohsa-hou with my child before bed every night. ... In addition, when we watch TV, I practice dohsa-hou with my son. However, I think it is easy to do it before bed. He relaxes well and I think it helps his better sleeping as well. If you relax, you would sleep better.” Another parent said, “My son’s most difficult issue is... ‘Not wanting to get off from a car’. It does not matter where we go. It happens anywhere. Especially, it happens more at unfamiliar place. For example, getting off a car at an unfamiliar place. He is afraid of it a lot. ... I tell him to lift and put down his shoulders to relax on them and breathe peacefully for 5 to 10 minutes in a car on the way to his school. He follows my directions very well.”

Some of the parents noted that they used dohsa-hou for themselves. They said that they believed that they got benefits from the dohsa-hou movements. For example, they took a time to focus on themselves, to have a deep breath and to relax when they encounter a situation that made them anxious. One parent said,

I also advantage from the use of dohsa-hou. I use dohsa-hou for myself to calm myself down. For example, when I stand in front of people or wait for some, I get anxious and feel like butterflies in my stomach. Then, I try to ease on my shoulders and feel calmed. And, ... parents’ feeling would be recognized to their child. Children pick upon what the parent is feeling. When parents sit with their child, the child would be calm if the parents are calm. So... I use dohsa-hou for myself and then use it for my child.

To sum up, most parents who took part in this study showed that they were familiar with the concepts of dohsa-hou, that dohsa-hou was useful to their children in everyday life, and that they were willing to continue to use dohsa-hou. They understood that their children with ASD suffered confusion in their communities, anxiety from the confusion, and stiffness from the anxiety. They believed that dohsa-hou was a way of helping to relax, to control their anxiety, to be patient to listen to and look at the world, to understand the world and finally to be able to communicate. They expressed how effectively they were able to use it. Dohsa-hou was in use in their everyday lives, such as before bedtime, during transportation, and in any of uncomfortable circumstances. Some of parents stated that they practiced dohsa-hou for their own benefit.

As noted above, participants provided information relating to dohsa-hou but they also provided information not relating to dohsa-hou. In the next chapter, results from the data will be discussed, particularly the findings from data not related to dohsa-hou.

## Chapter VI

### Findings not Related to Dohsa-hou

In addition to their perspectives on dohsa-hou, all the parents shared their thoughts on other areas not specifically related to dohsa-hou. These included how they had tried to understand: (a) what ASD was to them, (b) why their children acted differently, and (c) how the people in their home communities responded to their children.

First, they emphasized that ASD needed to be understood as a different state and not as strange, weird or wrong. Most of the parents did not know about ASD at all before their child was diagnosed as having ASD. Only two parents reported that they had previously met children with ASD through work or family. Even those two parents did not have any clear idea about ASD. According to the parents, they went to see a doctor because they noticed that their children were delayed in communication and social skills. When they visited their doctors, the doctors assessed and diagnosed their child. The parents had a vague suspicion that something was wrong and were afraid to have their child diagnosed. However, the parents reported that they found peace of mind after their child's diagnosis because they knew what they were facing. They then studied ASD, searched for resources for their child and shared their personal cases with other parents. All parents shared their perspectives on ASD through their experiences with their sons and daughters. According to them, children with ASD understand the world, but not in the same way as others do.

Second, according to the parents in this study, their children with ASD were healthy and energetic, like other children were, not ill. Third, some of the parents shared their personal perspectives about their communities and how their children were accepted or not.

### **Parents' Perspectives on Autism Spectrum Disorder**

Countries that use Chinese characters (i.e., Hanzi in China, Kanji in Japan, and Hanja in Korea) translate the word 'autism' as 'locking oneself in the self'. The awareness of ASD was manifested in Asia in the 1980s (Sun & Allison, 2009; Elsabbagh et al., 2012). The common understanding of the meaning of ASD mirrored perspectives in North America and Europe. People understood that children with ASD spent time alone, did not want to communicate with others and were not willing to understand the world. People thought that individuals with ASD were too shy, too selfish or too ignorant of others and their surroundings. As noted earlier, perspectives about what ASD have changed over time. These days, ASD is understood as a neurodevelopmental disorder. Neurotransmitters are the brain chemicals or chemical messengers that communicate information throughout our brain and body. They support development in language, social and cognitive skills (Carlsson, 2001). According to the parents in this study, the neurotransmitters in their child did not work properly. Parents noted that children with autism had higher or lower sensitivities than children without autism. Due to these sensitivities, children with autism experienced higher anxiety and adopted bodily postures and positions that appeared uncomfortable. All parents noted that their children showed a high level of anxiety. They said that their children were challenged by changes in life, became anxious, and then overreacted. One of the parents mentioned that due to their sensitivities, children with ASD literally saw the world differently, acted differently and showed anxiety. The parent said,

Autism... I think is not normal on all senses such as the sense of hearing, sight, touch, taste, and smell. They see what we don't see. They don't hear what we hear. Or they hear too sensitively what we don't hear. We hear what we hear but they can hear all the background sounds so they cannot hear what they are

supposed to hear. Because they are all mixed up. And... I think the criteria to decide the level of autism is the sense of sight. I think their level gets different depending on how much they can see. Like us, we can see an angle of 180 degrees. Even though I look forwards, I can notice what is happening on my side. But, in my child's case, only looking forward can be difficult. I heard that their spatial sense is different. Concepts of space? For example, these two pens are put 3 centimeters apart. He might feel that they are close or very much apart. The process of observing and recognizing stuff is runs differently. And, they have different sense of color. We see this as white but he might see it as another color.... They are locked in themselves because they have unbalanced senses. Because of it, they do not see the truth right, and their recognition is twisted. If my son shows some weird behaviour, there must be a reason for it. But, I don't always understand him. But... it is right for him.

According to the parents, their children understood the world differently and became afraid and anxious as a result of their neurodevelopmental disorder. They encountered this 'weird world for them' all the time. Finally, their behaviours or reactions looked unusual and might not be acceptable to other people. As one parent said, "It is difficult to understand him perfectly. If it is something he used to do, it is okay. But, if it is different than usual, he goes into a condition of 'zoned out'. He goes to 'his mental zone' because he doesn't know the reason why he is there."

Another parent said,

There was a room he couldn't go in. But, now, he can after he practised to go in.

The floor was covered with linoleum. He could go into the room in daytime.

However, if the light was on due to the cloudy weather or darkness, the ceiling

light was reflected on the floor. Then, he could not go into the room because of the reflection on the floor. He was too sensitive. He overreacts to anything. He was difficult to deal with.

According to the parents, children with ASD had difficulties understanding the world and those difficulties created communication barriers with others. The result of those barriers could be seen in behaviours such as screaming, no-reaction, and so on. The barriers were exacerbated by the ignorance of others on how to react appropriately. Finally, some parents thought that other people thought people with ASD were weird or wrong because they were different.

### **Children with Good Health and High Energy**

All parents who took part in this study stated that having ASD was like understanding the world differently and acting differently, and was not the same as being sick. The parents noted that their children with ASD were in good physical health, athletic and energetic. One mother said, “My child is healthy. He usually comes home at 2:30 or 3 pm after school. He goes swimming once a week. He rides on a bike home for 8 kms every day. It usually takes 30 minutes. I let him do it every day to use his energy and he has a bath. He sometimes runs the marathon with his dad but usually runs 8kms on a home machine.” As the parents said, they initially took their child with ASD to a doctor because they noticed mostly delayed language development, not because the children were sick. One of the parents mentioned that

He was born without any issue. He grew up healthy. ... I believe he had an impaired brain since he was born. It was not shown when he was assessed but... Because of it, he seemed to be born normal and did not show anything weird.

However, I realized that he was delayed when he was 1 year old. I thought it was strange but he was potty trained before he was 24 months old. Therefore, I did not think it was that serious. Then, when he was 24 months old, he was much more delayed than other kids were. Comparing to children who develop normally, he was a lot delayed on interaction and language. We went to a hospital when he was 30 months old.

According to all parents in this study, ASD was not something that was diagnosed at birth like other disabilities or illnesses. It was something that was noticed through certain unusual behaviours and the appearance of different language development. For these parents, their children were not ill, but rather their children had ASD, were in good health, and had lots of energy.

### **Diagnosis for Service**

Some of the parents emphasized that they used doctors' diagnoses for more support from the government for their children. However, they stated that doctors' diagnoses were unclear and that they did not trust them. One of the parents said,

I honestly do not think diagnosis is important. We have criteria of seeing autism but the decision-making is up to doctors. You would get a different diagnosis from different doctors. He was diagnosed as having developmental disability at our first visit (at the age of 30 months). He was diagnosed as having autism when he was 4 years old. The reason why we went for his diagnosis was for his additional education. Once you get diagnosis, you can get additional education for children with disabilities. Children who are diagnosed having severe disabilities do not need to pay for their additional tuition fee. ... To enter an inclusive day care, we had to go for another diagnosis. He was diagnosed with

the second level of autism. A doctor said, “This child reacts some and repeats what we say so he will get the third level.” However, my child got the second level. ... I am not saying that I am not satisfied with the diagnosis. But... the doctor was surprised with my child’s behaviour because he ran away in his barefeet. I think he diagnosed my child as having the second level because of it. He was diagnosed the second level when he was 4 years old. ... There is an activity support program. ... The program is only for children with the highest level, the first level. To get the support, we went for another diagnosis to get the first level of his disability.

According to the parents, a diagnosis of ASD was needed to seek better services. The parents needed supports and expected that their children would have a better life with better services.

One other point to highlight is that they see the world differently as having a child with ASD. They see their child as a person, a healthy person, like other parents of children without ASD or other disabilities do. The parents do not see their child as a bad kid or problem like others judge their child. The parents require the right service and education as other parents of children without ASD or any other disabilities do, The parents who took part in this study might have different perspectives on ASD if they did not have the child with ASD. However, they would not be different to look for engaging enjoyable activities for their child, bonding with their child, and becoming closer to their child. They are real persons.

### **Complaints with Societal Understanding and Acceptance**

According to some parents, it seemed that many people did not appreciate the realities of living with ASD. The parents noted that there was still a lack of understanding of autism in

society. Although ASD had appeared more often in the population, and people were trying to learn more about it, people still did not understand the behaviour of children with ASD and judged them. One parent said,

Children like my child are difficult to take anywhere because they show their dislikes although they look just like other kids. For example, hitting something, running away, throwing things ... Then, people think about the situation. 'This kid hits. Let's do something not to be hit.' I do not say that the people are bad. But... the hitting comes out when he is in a difficult or awkward situation. So I think ... If people can prevent him to not be in the situation, it would be carried out. I am not satisfied with the fact that most people do not think and act that way in the real world. I often hear, "Hitting is bad. This kid is bad." I want to say, "It is not him who is bad. You put him in the situation that made him upset. You who put him in the situation are bad. You are bad!" but I stay in silence. My child did not make the situation on purpose. It happens and finally makes the other person mad. My son just sits there but it makes the other person upset. If the person fully understands what autism is, it would not go into a bad situation. I hope there are more people who understand what autism is. ... Making others mad is an unpleasant thing. Despite he did not mean to, when something is broken ... he already feels sorry about it. However, people tell him, "You broke it!" Then, will be really mad at himself and the situation gets worse if people blame him although he already feels bad and guilty about it. ... Being able to walk does not mean that he is able to do anything.

Some parents noted that we still live in a world that does not understand or accept differences. The parents were upset about the reality of the lack of understanding of ASD. Some of

them stated that it is the world we are living in and that it was the reality they had to accept. One of the parents, who expected their child to accept the reality of the world said, “There is nothing I can do when something unfair happens to my child. I think he needs to accept the reality although he gets emotionally and sometimes physically hurt.” Parents in this study complained about the lack of societal understanding and acceptance, but did not suggest making it better. Rather, some of the parents mentioned that they taught their children to accept the reality because the parents accepted that it is the way it is.

### **Complaints with the Service System**

According to most participants, services and programs were developing constantly; but there were not enough to meet the needs of children with disabilities and their families. Parents who took part in this study noted that families required more services, respite workers, program staff, and teachers educated to meet the needs of children with disabilities and their families. One parent said,

I still feel lack of support for children with autism. ... There is a lack of respite workers who understand children with autism. I need support to take care of my son often but there is almost nowhere to go. This is very difficult. And... sad. ... there are still teachers who don't understand children with autism well. The fact sometimes makes me upset. 'Hmm. Yes. They still do not know yet. They don't know autism.' It sometimes happens.

Some parents complained about teachers' attitude towards students. According to them, not all teachers tried to educate students with care and parents could not expect all the teachers to work hard for their children. One parents said,

There is not enough support for my son. There are different types of teachers.

Some of them try to do more things with parents. Some of them do just what they do. Some of them do less. I have met several teachers and they were all different. I have met a term teacher. Term teachers are powerless. They do not speak up at school. Our children spend most of their time each day at school. Then, they should get more systematic and various programs but it is more like killing time at school. That is what I feel about school. I expect more a visionary and creative system at school but the reality is that it is only idealistic. The only thing I can do is to trust teachers and to leave them to do what they do. But it is also difficult to trust them fully. You know. Each teacher has a different level of responsibility and passion. So if I meet a passionate teacher, it will be a happy year. If not, it will be just a holding year to the parents.

The parents described teachers who focused on theories of special education and the educational program itself, but not on the child. One parent said,

I usually do not watch my child's class but I stole a peek one day. I saw that my child's speech therapist was talking on the phone in the class. For 30 minutes of the one hour class! I was upset so I talked to the teacher. She hid the truth that she was talking on the phone. I told her angrily that I saw the entire scene. Well, she said that my child had been good in the class and I got so angry the calm way that she lied about. So, I just walked out of the building with my son. Since then, the centre has adopted a policy not to answer the phone during classes. I think the director of the centre heard about it. ... My child was wandering around in his music class with two teachers. I do not know why there was an extra teacher but they tuned together. One of them was playing a piano and the other was playing a

guitar. My child was constantly walking around. I asked them what they were doing. The teacher told me that listening to music was also learning.

Most parents complained not only about the lack of services, including program staff and respite staff, but also the lack of knowledge of teachers and practitioners. Their perspective was that they required more staff and services and better education on ASD for staff and practitioners.

### **Summary**

In this chapter, I presented three main points: 1) parental perspectives about dohsa-hou, 2) parental perspectives about ASD, and 3) parental perspectives about societal responses to their children with ASD. In this study, I recruited parents of children with ASD and focused on dohsa-hou as a response to ASD. Parents in this study shared their thoughts on ASD, their children, and approaches that they had used. However, the parents did not limit their thoughts to ASD. They talked more about the need for a better quality of service and better understanding of people with ASD in their communities. Their common thoughts included wishing their child to have better supports for a better life in general. For the parents, this meant not only better education and support, but also greater community acceptance and support. The parents admitted their children's disability and wanted to help their children for an easier life.

I learned that the parents were passionate about sharing their experiences and stories. They were not shy to take part in the study and they were very keen to share their experiences. As one of the parents mentioned, "When I talk about my child, I feel relaxed. During that time, I realize about my kid again. I get a chance to think about my child with this opportunity. I can think even what I haven't thought about."

In the next chapter, I will present conclusions and explore implications and limitations from the findings of the study.

## Chapter VII

### Conclusion

In Chapter I, I looked into different theoretical and professional perspectives on ASD. In Chapter II, I looked into various approaches to treat individuals with ASD and introduced dohsa-hou. In Chapter III, I described how I carried out this study. In Chapter IV, I described the participants in this study. In Chapter V, I reported on parental perspectives to explore if dohsa-hou is helpful for children with ASD. In Chapter VI, I included parental thoughts not relating to dohsa-hou. In this concluding chapter, I will examine the findings and explore the implications and limitations of this study.

Parents in this study were eager to tell their stories. They seemed to be glad to have a chance to express their thoughts. The mothers expressed what they were thinking of, what they were satisfied with, and what they were not happy with. They also discussed the changes that they would like to see in the service system and in society at large. Through this study, we can hear their voices. They are not simply program receivers or caregivers. They are parents who have chosen to use a particular therapeutic approach with their children who have ASD. They want to participate actively in their children's education and therapies, not just step aside and watch. Although they are not professionals, they have the right to express their opinions on what they are using with their son/daughter with ASD. Their perspective remains valid, valuable and worth our attention. After all, therapeutic approaches are developed for individuals with ASD and their families, not for professionals or doctors.

There are three major themes from the findings of this study: 1) parents' perspectives of ASD, 2) the relationships between dohsa-hou and their children with ASD, and 3) the positive effects of dohsa-hou on their children with ASD. They showed their understanding of their

children's ASD. They also discussed their beliefs about the relationship between dohsa-hou and their children's abilities to interact with others (e.g., listening to others, initiating communications, interacting with others, and participating in tasks). These parents also had perspectives about the possible relationships between dohsa-hou and their children's self-awareness (e.g., posture, movement, and bodily self-awareness). Parents in this study admitted the reality of their children's disabilities. They also wanted their children to have a better life. They believed that dohsa-hou is one of the ways that they can help their children have an easier life.

### **Parents' Understanding of ASD**

Parents in this study described 'living with ASD' as their child 'locking oneself in his/her own world' or 'living in oneself's own world'. The parents' understanding of ASD does not seem to differ from that of parents in western culture. According to Roberta, Christine, and Loretta (2008), 'living with ASD' is thought to be 'living in a world of our own'. The understanding of ASD in Asia seems to be similar to the understanding of people in other countries. The understanding of ASD in Asia may have evolved within a wider international understanding due to the influence of the International Classification of Diseases (ICD) of the World Health Organization (WHO) and the Diagnostic and Statistical Manual of Mental Disorders (DSM) of American Psychiatric Association (APA) (Sun, & Allison, 2009; Elsabbagh et al., 2012).

Parents in this study did not blame anything or anyone for their children's ASD. They were not angry at ASD, God, or anything else. They admitted the fact that their children were different from children without ASD, but did not see their children as sick. They maintained that their children are ordinarily healthy and even more athletic than children without ASD. They understood that ASD is a prolonged or lifelong characteristic. The mothers in this study looked

for approaches or therapies to help their children have an easier life. In addition to the above parental perspectives, I also looked more generally into parental perspectives about having a child with ASD in Western culture. There was limited materials on such parental perspectives but it was reported that Western parents valued their child having a better life and being happy as opposed to curing ASD (Poon, Koh & Magiati, 2013). Parents who took part in this study and parents in the above literature review (i.e., Parents in the Western culture) show similarity valuing their children's better life and wanting their children to be happy and satisfied. However, I note one difference. While parents from my study placed greater stress on the social participation of their child, the Western parents (Poon et al., 2013) placed more value on their child's personal satisfaction with life. For the parents who took part in this study, their children's ASD was not something to be cured; however, the parents believe that their children could have a better life with help. The parents did not look for or use approaches and therapies that would "change" their children or "cure" them.

A neurological perspective on ASD seemed to be the dominating theory with parents in this study. Parents in this study said that their children with ASD had different or abnormal sensory systems that altered how they recognized and understood the world. The parents also believed that the different sensory reactions of their children led to their anxiety and that the anxiety made situations worse. The parents thought relaxation and gentle movement guidance seemed to be one way to help their children. They saw dohsa-hou as one of the ways to help their children manage their ASD more effectively.

### **Parents' Understanding of the Relationships between Dohsa-hou and ASD**

The participants believed that dohsa-hou was helpful for their children with ASD, to have a better life, to connect with other people and to better understand the world while many

researchers focus on the ASD itself, these parents were able to focus on their children who live with ASD. For them, dohsa-hou is not a cure for ASD, but it does bring hope about the possibilities for and potential of their children. According to the participants, dohsa-hou also offered a way to understand and to communicate with their child. To promote the potential of one child with ASD, it could be combined with other various approaches. For example, a child with ASD has the goal to go and enjoy shopping but is afraid of walking in crowds. The use of dohsa-hou could be combined with social stories for the child to become more tolerant of contacts with people and the activity level at a public shopping mall. In a shopping mall, there are various kinds of potential reasons to be stressed about such as crowds of people, different colors, different lights, noise and non-understandable social stories for the child. The combination of dohsa-hou and social stories could be helpful for the child to be relaxed, tolerant and enjoy shopping.

### **Parents' Beliefs on the Positive Effects of Dohsa-hou on the Children with ASD**

The parents saw that Dohsa-hou was effective in the following ways. 1) greater relaxation, 2) better self-awareness, which helps the child become more tolerant and accepting of change, 3) better communication skills and 4) a joyful activity that their child wanted to continue.

Parents described that the sensitivity of their child with ASD to sensory information was higher or lower than other children. Due to this, their child experienced unnecessary tension and unbalanced physical growth such as tensed and curved shoulders and back. The tension and the different level of sensitivity disturbed their child and made it hard for them to accept changes, understand others and found that each situation became difficult to handle. Finally, their child experienced difficulties in communicating and interacting with others.

However, the parents saw that their child experienced greater relaxation from the use of dohsa-hou and they believed that their child got positive thinking and feeling. They believed that their child had better self-awareness of themselves while focusing on their body movements.

They also believed that the better self-awareness allowed their child to better understand others and various situations, to accept changes and to have better communication skills. Furthermore, the parents thought that the use of dohsa-hou was a joyful activity to be able to continue to do for their child with the positive thinking and feeling from the greater relaxation from it. The joy that the mothers described may be an unintended consequence of using dohsa-hou. Other unintended consequences include the fact that taking part in dohsa-hou offered the parents some respite, the opportunity to gain peer support from other families and an important way to be close to their son or daughter (physically and emotionally). According to the mothers, both they and their children enjoyed and appreciated the use of dohsa-hou as a 'joyful activity'.

### **Implications**

The findings from this research study have implications for three different areas that are readily identifiable. The results of this study have implications for service providers, policy makers, and researchers.

#### **Implications for service providers**

Findings generated from this study provide insight into what the parents think service providers should be aware of. According to the parents, service providers need to study ASD and understand individuals with ASD and their lives. Some of parents who took part in this study said that they were not satisfied with the attitudes of some service providers, nor with the amount of services available to them. While parents discussed dohsa-hou practitioners most, they also referred to all service providers. Children with ASD and their families meet service providers on a daily basis. The providers can be teachers, practitioners, therapists, doctors, nurses, respite workers and social workers.

In order to improve its effectiveness, dohsa-hou can be initiated and used in multiple

settings and environments, such as the clinic, home, school and community rather than limited locations. Dohsa-hou is now used formally in camps, clinics and homes, and informally in community settings by parents. There is no reason it could not be used in schools. It has a multiple-setting viability advantage over some other approaches. Furthermore, it does not have side effects and it benefits parents and caregivers as well as children with ASD. If the use of dohsa-hou could be merged with other approaches and classes in schools, it has the potential to benefit children, teachers and caregivers. The specific implications for service providers are discussed below. These include access to dohsa-hou, understanding ASD, understanding dohsa-hou, education of dohsa-hou for parents, family support programs and funding.

**Accessibility to dohsa-hou.** Parents in this study commonly noted that there were not enough resources to access the use of dohsa-hou. There were not enough practitioners and places to provide the service. The lack of practitioners and places resulted in a lack of opportunities to practice dohsa-hou. It is expensive for parents to have their child go to a dohsa-hou class, attend a camp and convene parental meetings. The expenses also limited access to practice or to learn to use dohsa-hou. Travelling to take a class or attend the camps sometimes was required because there were no closer resources available. For the parents in this study, dohsa-hou service providers need to develop greater and easier accessibility.

**Better understanding of ASD and individuals with ASD.** According to the participants, service providers need to have a better understanding of ASD and children with ASD. The parents believed that this will improve services. Some parents who took part in this study mentioned how the service providers' lack of understanding of ASD, and children with ASD, negatively influenced their children. For example, a dohsa-hou practitioner needs to understand what ASD is and how ASD influences each child differently before the practitioner uses dohsa-

hou with a child with ASD. To promote the effectiveness of dohsa-hou on children with ASD, practitioners need to understand how children with ASD understand their “world” and how they react to it.

**Better understanding of dohsa-hou.** According to the parents who took part in this study, dohsa-hou is a communication strategy, not just a way to teach physical relaxation. Dohsa-hou practitioners need to be able to use dohsa-hou properly and effectively. Practitioners need to be experts in how to communicate effectively with every child during the practice of dohsa-hou. Practical knowledge should be used in conjunction with theoretical knowledge to use dohsa-hou for children with ASD. According to one parent, each practitioner should know not only how the structure of the body works but also to be able to communicate with each child.

**More education needed.** Parents who took part in this study wanted dohsa-hou service providers to provide more practical and theoretical information about dohsa-hou to the families. The parents felt that dohsa-hou was effective for their children and themselves, but had difficulties in describing how dohsa-hou worked for their child. They wanted to develop a better understanding of how dohsa-hou works. Further, parents in this study wanted other parents to have the opportunity to learn about dohsa-hou. They wanted to share the opportunity to experience dohsa-hou and their feelings of satisfaction with other parents. Parents in this study wish that the use of dohsa-hou could be extended to others. These parents want to promote and advocate the use of dohsa-hou. To ensure better trained dohsa-hou practitioners and better understanding of dohsa-hou by practitioners and parents, some of parents recommended that universities offer classes or programs in dohsa-hou.

**Family support programs.** According to the participants, more family support programs are required in order to extend dohsa-hou practice. According to parents in this

study, using dohsa-hou daily at home is the most effective approach. However, not all the families are able to support their child with ASD by using dohsa-hou in daily life. In this study, some mothers practiced dohsa-hou with their children. In some cases, fathers also participated in the practice. Family support programs in the use dohsa-hou would be helpful to promote the practice with siblings, grandparents and other family members.

**More funding.** According to some parents in this study, more funding is required for more access to dohsa-hou classes, meetings and training. They hoped that, in the future, there will be: (a) more staff and places to do dohsa-hou, (b) more opportunities to attend classes, meetings, and camps, (c) more and better training for practitioners and families, (d) lower fees, and (e) dohsa-hou classes or programs established at universities.

### **Implications for policy makers**

This study has four implications for policy makers. The implications are based on the parents' perspectives in this study. According to the parents in this study, parents receive different services in South Korea and Japan. Families in Japan seem to have more financial support and more information to support their children than families in South Korea. Although there was a difference between the two countries regarding support levels, parents in Japan who took part in this study also wished to have more support for their children. The main theme of this implication was respect.

**Policies for people.** Policies for people with disabilities and their families are meant to support people with disabilities and their families. However, it does not always seem to work that way. Some parents who took part in this study did not say directly that school or government policies did not protect them, but implied that they did not always feel that the law or policies supported or protected them or their children. For example, some parents in this study complained

about some teachers' attitudes in schools. According to the parents, they had to absorb their anger and frustration when something unfair happened to their child. Pursuing their concerns would require a formal process with the school system and they did not want to get involved with such a process. School systems must ensure that all staff are prepared adequately for their roles as educators, including teaching children with ASD. In other words, both attitudes and competencies must be addressed.

### **Implications for researchers**

Lastly, this study implies a number of things for future research. As this study has little data on the general efficacy and effectiveness of dohsa-hou, more studies are needed. As noted in Chapter II, researches on dohsa-hou have been based on observation and progress notes. To determine the effectiveness of dohsa-hou, future studies should include more visible and measurable data (i.e., MRIs, pictures, and graphs) regarding the changes or effects on people with ASD as well as the perspectives of various groups of people. First, visualizing the correlation between the effects of dohsa-hou and the various life areas of people with ASD will give us a way to measure the effectiveness of dohsa-hou for people with ASD. Second, studies on dohsa-hou may offer practical aspects of dohsa-hou for people with ASD if future studies include the perspectives of various groups of people. The various groups include people with ASD, people with other disabilities, athletes, various family members, and families and/or individuals who choose not to use dohsa-hou. It will be valuable to know how the users of dohsa-hou actually feel about it. This means that people with ASD who use dohsa-hou have good opportunities to tell their own stories. The perspectives of the recipients of dohsa-hou themselves will provide an important insight into what they actually experience after the use of dohsa-hou and how the use of dohsa-hou affect their mind and bodies. While parental perspectives are also valuable to document the effectiveness of dohsa-hou it will be the perspectives of the dohsa-hou users with ASD that will

provide more direct information about the use of dohsa-hou. The participants of this study were all mothers of children with ASD. Having opportunities to hear fathers, siblings and other close family members' voices will give promising perspectives. The perspectives of people who decided not use dohsa-hou will also allow us to acknowledge the limitations of dohsa-hou.

According to research, dohsa-hou has been used with people with other disabilities (Kumar, Harizuka, Furukawa, Kim, & Kumar, 2005; Lee & Cho (2002); Naruse, 1995) and athletes (Yamanaka, 1992; Dadkhah & Harizuka, 1997). Adding to, the perspectives of people with other disabilities and athletes would be helpful to learn how dohsa-hou works for them.

### **Limitations**

I encountered some limitations in carrying out this study. There were two types of limitations. This first was who actually took part in this study. The second relates to the fact that data were collected in Korean and Japanese and then translated into English.

### **Participants**

The small number of participants in this study limits my ability to represent the perspectives of all dohsa-hou users' parents. Although the number of participants might not be enough to understand general parental perspectives on dohsa-hou, I believe the findings from this study are valuable to understand the participants' perspectives of their children with ASD and the impact of using dohsa-hou.

As I noted earlier, I learned that the people who distributed the recruitment materials in Japan only contacted ten families initially, all of whom agreed to take part. Staff at the organization in Japan asked me how many participants I would need for this study. I told them that I had intended to interview at least ten parents. The recruitment materials could be distributed randomly or selected. I do not know how the people were selected to receive the

recruitment materials. The recruiters thought that there would be a high interest and demand to take part in the study and apparently wanted to save me the trouble of turning people down.

As noted in the findings for this study, only mothers were interviewed. I did not limit the participation in this study to mothers. However, the exclusive participation of mothers might be because they are more likely to attend the annual dohsa-hou camps with their child than the fathers. Parents who took part in this study mostly chose to have their interviews conducted at the dohsa-hou camps. Alternatively, it might be because mothers are considered the spokespersons in their family. In South Korea and Japan, it is the mothers' responsibility to represent their family and the family's interests, and the study participants did exactly this. However, other perspectives will be needed to understand the various aspects of dohsa-hou. There must be perspectives of fathers, grandparents, and/or caregivers in order to get a fuller picture. Furthermore, it will be valuable to look at the perspectives of other groups of people such as siblings, people with ASD, dohsa-hou practitioners, and parents who did not choose dohsa-hou.

There were some parents in Korea who did not have a chance to take part in this study because of the inclusion criteria. Even though I stated that the interviews would be looking into parental perspectives of children with autism, there were still some parents of children with other disabilities in Korea who were interested in this study. I appreciated their interest even though they did not have the chance to participate.

### **Language and Cultural Context**

Language was another limitation in this study. I translated the recruitment and consent letters from English to Korean. I used a free, publicly available electronic translator app (through Naver.com) to translate the Korean text into Japanese. In Korea, I conducted the interviews in

Korean and translated them into English. In Japan, a Korean Japanese translator was also present. I asked questions in Korean, these were translated into Japanese and then the parents' responses were translated into Korean. Ultimately, I translated the Korean into English. As noted in Chapter III, I hired a translator who is familiar with both Japanese and Korean culture as well as dohsa-hou. I also hired a transcriber who is familiar with Asian culture to minimize the danger of missing semantic nuances that were in the interviews. Despite these precautions to ensure the data were accurately translated and contextualized, I cannot avoid the reality that multiple translations of narrative text data meant some fine nuances were perhaps lost. This study started in the Fall 2015. During the early analysis process, I had to go through each transcription myself, and then with the transcriber, to make sure that what the participants said was accurately represented and that the translations made sense in English.

Furthermore, data are always a snapshot of the thing being studied. The data are now a year and a half old, but are nevertheless grounded in the perspectives of parents of children with ASD.

### **Summary**

Parents expressed their wishes for their children to be able to use dohsa-hou in a variety of settings in their everyday life. The parents also wanted their neighbors and community members to be respectful and supportive of their family life and accepting of their child with ASD. They also wanted to be respected in their roles as parents.

There are various approaches and therapies known to be helpful for children with ASD. For the parents in this study, they adopted approaches only when they saw clear benefit for their child with ASD. For these parents, dohsa-hou gave them a way to participate actively in their child's life, to understand and communicate with them. Using dohsa-hou provided the parents

with a tangible way to support and help their child with ASD.

Determination and advocacy can be powerful for individuals with ASD and their families. In general, there are many parents and families who tend to listen to what professionals say and follow what they are told to do without critically thinking about it. According to some parents in this study, many parents are afraid to speak up and give an opinion in front of service providers (eg. doctors, practitioners and therapists) because they might lose their service opportunities. For example, one participant recommended using dohsa-hou to her friend who had a child with ASD. The friend asked her child's physiotherapist what if they could try dohsa-hou. The therapist did not like the idea. The therapist thought that dohsa-hou was similar to physiotherapy and did not understand why the parent wanted to try out another approach even though the child was already having physiotherapy. The parent decided not to try dohsa-hou as she did not want to lose existing services for her child. For the parents in this study, standing up for what they thought best for their child with ASD was essential.

The parents in this study reported that dohsa-hou has helped their children and themselves. They did not mention how dohsa-hou related to ASD itself. However, they did mention that dohsa-hou was a helpful way for them to understand their child and that it offered a better way to communicate with their child and to help him or her understand and communicate with others. They wished more parents and children with ASD could get the benefits from dohsa-hou that they had experienced. They wanted to share the good feelings and positive thoughts with other families. That is worth our attention.

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## Appendix A

### Letter to Presidents Permission to Conduct Study



Seonghwi Bang

Doctoral Candidate

Department of Inclusive Education

University of Manitoba

Canada

Date

Name of Director

Name of Organization

Dear Sir/Madam:

My name is Seonghwi Bang, and I am a doctoral student from the Faculty of Education at the University of Manitoba. I am writing to request your support for a research study. I am interested in parental perspectives on their experiences with dohsa-hou for their children. I am conducting interviews with parents of children with autism spectrum disorders (ASD).

The thesis project is entitled, "The Effects of Dohsa-hou: Parental Perspectives" and has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba.

The purpose of this study is to look at how ASD has been understood, responses to ASD, considered from an empirical standpoint and where dohsa-hou fits into these responses. To examine the effects of dohsa-hou approach, I will include parental perspectives on dohsa-hou. In

this study, I plan on asking parents if taking part in dohsa-hou affects the relational behaviours of their children with ASD. For example, the perspectives of the parents will be sought in order to examine 1) any possible relationships between the approach and their children's such as listening to others, initiating a communication, interacting with others, and participating in tasks and 2) if they think their children's self-awareness of their body image and frame changes during and after dohsa-hou (e.g., posture, movement, and bodily self-awareness).

There is minimal risk involved in this study to any participant. Some parents may find interesting to reflect on their experiences.

To help me in this study, I am requesting your support in helping me advertise this study to parents who have been using dohsa-hou for their children at least for one year. I have attached a recruitment letter that I would like to have forwarded electronically to parents of children with ASD. Essentially, parents who are interested in this study will participate in a face-to-face interview. I am also asking your help to arrange a private room in your dohsa-hou camp where I may conduct the interviews privately. Questions will relate to perspectives on dohsa-hou for children with ASD. Interviews will be done in the parents' first language (i.e., 1) Korean-conducted in Korean and I will translate into English. 2) Japanese – I will use an interpreter who will translate from Japanese into Korean and I will translate into English.) All interviews will be digitally recorded. Of course, participants will have the right to answer only those questions they feel most comfortable answering, and they can withdraw from this study at any time. The anonymity and confidentiality of all participants will be ensured. Please note that this research is primarily for my thesis dissertation but may be used later should I choose to write further publication on this topic for future journal article submissions.

Once the interested parents contact me, I will send the consent letter that includes the information and process of this study and an interview guide to them so that they have a greater understanding of the parameters of this study, and the ethical issues under consideration. Parents will have a chance to review the data. Once I complete all the transcription from the interviews, I will send the parents summary from the interviews to give them review the interviews.

The data will be securely stored in a Zip drive on a password protected computer file as required by the Tri-Council Policy Statement 2 (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). Only I will have access to all of the data and my thesis advisor, Dr. Zana Lutfiyya will have access to the anonymized data. My thesis committee members, Dr. Rick Freeze, and Dr. Emily Etcheverry, will have access to the anonymized data in the form of summaries and findings from the data. Field notes and transcripts will be written in Korean. The data will be translated in English and anonymized transcripts given to my thesis advisor, Dr. Zana Lutfiyya. All the written and digitally recorded data and transcription will be shredded and destroyed when this study is complete. I will make sure if I have completely destroyed all the data.

If you would be willing to help me advertise this study, please forward the recruitment letter to any and all parents with ASD who might be willing to help with this project. If you would prefer not to become involved, I thank you for being willing to consider my request. Regardless of the organization's formal involvement, I would be happy to forward a copy of a summary of the results of this thesis study once the thesis is complete.

The University of Manitoba may look at my research documents in order to make sure that my study is being conducted in an ethical and proper manner. This research has been approved by the Education/Nursing Research Ethics Board (ENREB). If you have any concerns or complaints about this project you may contact the Human Ethics Coordinator at [REDACTED], or by e-mail at [REDACTED]. You may also contact my advisor, Dr. Zana Lutfiyya, at [REDACTED].

Sincerely,

Seonghwi Bang

[REDACTED],

[REDACTED]

Tel: [REDACTED]

E-mail: [REDACTED]



상관없이 방문하여 인터뷰할 수 있습니다. 인터뷰는 한국어로 진행될 것입니다. 한국에서 시행되는 자폐 아동을 위한 동작법에 관한 관점에 관련된 질문들이 인터뷰에서 다루어질 것입니다. 물론, 참가하시는 분들께서는 편하게 느끼시는 질문에만 답하실 수 있는 권리가 있고, 어느 때라도 이 연구에서 빠지실 의향이 있으시다면 빠지실 수 있습니다. 모든 참가자의 익명성과 비밀 보장을 약속합니다. 윤리적 이슈에 대한 귀 기관의 이해를 돕고자 부모님들께 보내질 동의서를 첨부했습니다.

차후 연구, 특히, 저의 논문, 혹은 추가적인 자료를 위해 이 참가자들을 다시 모집하고자 할 수도 있습니다. 만약 이 일이 생길 시, 이 참가자들과 함께 저의 연구를 계속하기 위한 윤리 위원회의 승인을 다시 받도록 할 것입니다. 그에 더하여, 동의서에 참가자들이 차후 연구를 위해 다시 참여할 의사가 있는지 여쭙겠습니다.

귀 기관에서 이 연구에 대한 내용을 광고할 수 있도록 도와주실 의향이 있으시다면, 제 연구를 도와주실 의향이 있으실 부모님들께 제가 첨부한 광고문을 꼭 발송해 주시길 부탁드립니다. 기관에서 제 연구에 참여하길 원하지 않으시더라도, 제 요청을 참고해 주심에 감사드립니다. 귀 기관의 참여여부에 상관없이, 이 연구가 완료되는 대로 연구 결과를 요약해서 보내드리고 싶습니다. 감사합니다.

이 연구는 매니토바대학의 교육/간호연구윤리위원회(ENREB)에서 연구 진행 허가를 받았습니다. 만약 이 연구에 대해 제안점이나 불만사항이 있으시면, 위의 저의 지도교수님인 **Dr. Zana Lutfiyya** 에게 [redacted] 이나 인간윤리위원회의 담당자에게 전화 ([redacted])나 이메일 ([redacted])로 연락주시기 바랍니다.

진심을 담아 보냅니다,

방성휘 (Seonghwi Bang)

Tel: [redacted]

E-mail: [redacted]



インタビューは日本語で進行されます。動作法に対する経験をもとにご両親の観点を研究するのが目的なので、1年以上の動作法の経験があるご両親に限りインタビューをさせて頂きたいと思っています。

日本で施行される自閉性児童のための動作法に関する観点にかかわる質問がインタビューで扱われるでしょう。勿論、

参加する方々は答えられる質問にだけ答えていただき、もしこの研究への協力を途中でやめたいと感じれば、やめて頂けます。すべての参加者の匿名性と秘密保障を約束します。

倫理的事柄に対して、[redacted]に理解して頂こうと、ご両親たちに送る同意書を添付しました。

今後の研究, 特に, 私の論文,

あるいは追加的な資料のために、今回の研究の後、参加者の方々にはまた意見を求めることがあるかもしれません。そのような時には、

この参加者の方々達と一緒に私の研究を続けるため、倫理委員会の承認を再び受けるようにします。また、このことについては、

同意書で参加者の方に、今後の研究のためにまた参加して頂けることが可能であるかを質問するつもりです。

[redacted]にご協力頂けるならば、

私の研究を手伝ってくれる意向があるご両親たちに私が添付した広告文を必ず発送して下さるようお願い致します。もし私の研究への協力が叶わないとしても、私の要請を参考して頂けることに感謝いたします。

[redacted]の参加可否にかかわらず、

この研究が完了し次第に研究結果を要約して送付させて頂きたいと思います。よろしくお願ひします。

敬具、

この研究はマニトバ大学の教育/看護研究倫理委員会(ENREB)で研究進行の許可を受けました。

もしこの研究についてジェアンジョムや不満がある場合、上の私の指導教授の Dr.Zana Lutfiyya に [redacted] や人間倫理委員会で [redacted] や

[redacted] ご連絡お願い致します。

房 星輝 (バン ソンフイ, Seonghwi Bang)

[redacted]

Tel: [redacted]

E-mail: [redacted]

## Appendix B

### Recruitment Letter



#### **The Effects of Dohsa-hou: Parental Perspectives**

Dear Parents:

My name is Seonghwi Bang, and I am a doctoral student from the Faculty of Education at the University of Manitoba. I am inviting you to support for a research study. I am interested in parental perspectives on their experiences with dohsa-hou for their children. I am conducting interviews with parents of children with autism spectrum disorders (ASD).

Research project title: "The Effects of Dohsa-hou: Parental Perspectives".

The study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba in Canada.

The purpose of this study is to look at how ASD has been understood, responses to ASD, considered from an empirical standpoint and where dohsa-hou fits into these responses. To examine the effects of dohsa-hou approach, I will include your perspectives on dohsa-hou that you have used or received for your child. In this study, I plan on asking you if taking part in dohsa-hou affects the relational behaviours of your child. For example, your perspectives will be sought in order to examine 1) any possible relationships between the approach and their children's such as listening to others, initiating a communication, interacting with others, and participating in tasks and 2) if they think their children's self-awareness of their body image and frame changes during and after dohsa-hou (e.g., posture, movement, and bodily self-awareness).

Individual face-to-face interviews will take about 60 minutes. The time for the interviews will be at your convenience at the dohsa-hou camps. The location will be arranged in a private room at the camp site. The interviews will be digitally recorded and all data will be stored in my personal computer password protected securely all the time. In Korea, the interviews will be carried out in Korean. In Japan, an interpreter will translate for us. This individual will sign a confidentiality pledge. I will later translate them into English. You have the right not to answer any question or withdraw from the study completely at any time.

If you are interested in taking part in the study, I will send the consent letter that includes the information and process of this study and the interview guide to you so that you have a greater understanding of the parameters of this study.

Please note that this research is primarily for my thesis dissertation but may be used later should I

choose to write further publications and presentations on this topic for future journal article submissions. The data will be securely stored in a Zip drive on a password protected computer file as required by the Tri-Council Policy Statement 2 (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). Only I will have access to all of the data and my thesis advisor, Dr. Zana Lutfiyya will have access to the anonymized data. My thesis committee members, Dr. Rick Freeze, and Dr. Emily Etcheverry, will have access to the anonymized data in the form of summaries and findings from the data. The data will be translated in English and anonymized transcripts given to my thesis advisor, Dr. Zana Lutfiyya. Any data will be masked and all identifiers stripped from the analysis to ensure anonymity and confidentiality of participants. Only aggregate data will be reported to further ensure the confidentiality of participants. All the written and digitally recorded data and transcription will be shredded and destroyed when this study is complete. I will make sure if I have completely destroyed all the data.

Would you be interested in participating in a research study that is focused on parental perspectives on the relations on dohsa-hou and ASD and have a suggestion for individuals with ASD and the approach? If so, I would like to invite you to participate in this research project.

The University of Manitoba may look at my research documents in order to make sure that my study is being conducted in an ethical and proper manner. This research has been approved by the Education/Nursing Research Ethics Board (ENREB) If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at [REDACTED], or by e-mail [REDACTED]. You may also contact my advisor, Dr. Zana Lutfiyya, at [REDACTED].

If you are interested in participating, and want more information regarding the study, please contact:

Seonghwi Bang

Tel: [REDACTED]

E-mail: [REDACTED]

I look forward to hearing from you.

Sincerely,

Seonghwi Bang

Korean Version  
of  
Recruitment Letter  
인터뷰 지원자 모집



동작법 효과: 부모 의견을 바탕으로

참여자 귀하,

매니토바 대학교 교육학부에서 박사과정 중인 방성취입니다. 한국에서 시행되고 있는 자폐 아동을 위한 동작법에 대한 부모님들의 관점을 알아보고자 하는 연구에 참여해 주십사 하고 이렇게 글을 올립니다.

연구 제목: 한국과 일본에서 시행되고 있는 자폐 아동을 위한 동작법에 대한 부모님들의 관점

이 동의서, 즉 참고 자료로 귀하께 제공되는 이 서류는 연구에 대한 정보 제공 과정의 일부입니다. 귀하께 이 연구가 무엇에 관한 연구인지, 귀하의 참여가 어디에 참고가 될 것인지에 대한 기본 정보를 드리고자 함입니다. 만약 여기에 명시된 것보다 자세한 정보를 원하시거나, 여기에 명시되어 있지 않은 정보를 원하신다면, 언제든지 문의해 주시기 바랍니다. 이 동의서를 이해하실 수 있도록 자세히 읽어보시길 바랍니다.

이 연구의 목적은 한국과 일본에서 시행되고 있는 자폐 아동을 위한 동작법에 대한 부모님들의 관점을 알아보는 데에 있습니다. 이 연구는 1) 동작법과 자폐의 관계, 동작법이 아동들에게 미친 영향, 2) 그리고 동작법의 유효화를 위한 제안점에 대한 부모님들의 의견을 알아보는 데에 도움이 되리라고 봅니다.

연구 과정 중에 어떤 참가자에게 끼치는 위험 요소는 없습니다. 몇몇 부모님들은 자신의 경험을 되돌아보면서 흥미로운 점을 발견할 수 있을 것입니다.

이 연구를 위해, 최대 1 시간 분량의 면담 형식 인터뷰에 참여하실 분을 모집합니다. 최소 1 년의 동작법 경험이 있으신 부모님을 선착순 10 분에 한하여 인터뷰할 것입니다. 아버님과 어머님 두 분 모두 참여하시는 것도 가능합니다. 저는 서울이나 캠프에서의 인터뷰를 선호하지만, 부모님께서 원하신다면 어느 장소이든 상관없이 방문하여 인터뷰할 수 있습니다. 인터뷰는 한국어로 진행될 것입니다. 한국에서

시행되는 자폐 아동을 위한 동작법에 관한 관점에 관련된 질문들이 인터뷰에서 다루어질 것입니다. 물론, 참가하시는 분들께서는 편하게 느끼시는 질문에만 답하실 수 있는 권리가 있고, 어느 때라도 이 연구에서 빠지실 의향이 있으시다면 빠지실 수 있고; 연구에서 빠지시길 원하신다면, 귀하께서 주신 정보는 모두 삭제될 것입니다.

귀하께서 편하게 느끼시고 인터뷰 내용의 비밀 유지를 위해 저와 귀하께서 모두 동의한 인터뷰 시각과 장소를 정할 것입니다. 인터뷰는 디지털 녹음기로 녹음될 것입니다. 인터뷰에 앞서 질문에 대한 답변을 생각하고 정리하실 시간을 위한 한국어로 된 인터뷰 질문지가 이메일을 통해 발송될 것입니다. 귀하의 익명성 보호는 계속 유지될 것입니다. 귀하의 익명성을 위해 가명이 사용될 것입니다. 귀하의 인터뷰 내용은 저를 통해서만 문서에 옮겨지고 분석될 것입니다. 답변 내용을 귀하께서 추가, 삭제, 혹은 변경하실 수 있도록 하고 빠진 부분이 없는지 확인하기 위해, 귀하의 인터뷰 내용이 옮겨 적힌 문서를 보내드릴 것입니다. 이 문서는 인터뷰 자료 분석을 시작하기 전에 발송될 것입니다. 이 연구를 위한 자료는 저를 통해서만 분석될 것입니다. 귀하의 인용문을 직접 사용할 수도 있습니다. 귀하의 참여 비밀보장을 위해 통합 자료만이 발표될 것이며, 귀하의 성함은 자료의 어디에도 표기되지 않을 것입니다. 모든 자료는 저의 집에 있는 개인 컴퓨터에 비밀번호로 잠금 저장될 것이며, 어떠한 기관에게도 신분 정보 노출을 하지 않을 것입니다. 개인정보 노출이 생기지 않도록 꼼꼼히 검토될 것입니다. 단, 저의 지도교수님, **Dr. Zana Lutfiyya** 만이 자료를 열람할 것입니다. 혹시라도 귀하의 신분을 노출시킬 만한 자료는 자료 분석시 사용되지 않을 것입니다. 자료를 통한 연구 결과는 저의 논문, 혹시 있을지 모를 발표나 저널 게재를 위해 사용될 수도 있습니다. 녹음된 인터뷰와 그 내용이 옮겨 적힌 문서는 저의 논문이 완료되는 대로 철저히 삭제될 것입니다.

한국어로 결과 요약본이 정리된 문서를 받기를 원하신다면, 이 연구가 완료되는 대로 귀하께 발송해 드릴 것입니다. 발송은 귀하께서 원하시는 방식으로 우편 혹은 이메일로 발송될 것입니다. 이 연구는 교수/학문연구회이나 저널 게재에서 발표될 수도 있습니다.

추후 연구, 확실히 말해서, 저의 추후 논문이나 추가 자료를 위해 귀하에게 다시 협조 요청을 할 수도 있습니다. 만약 이 일이 생길 시, 여러분과 함께 저의 연구를 계속하기 위한 윤리 위원회의 승인을 다시 받도록 할 것입니다. 그에 더하여, 동의서를 통해 여러분께서 차후 연구를 위해 다시 참여할 의사가 있는지 여쭙겠습니다.

이 서류에 서명하신 귀하의 사인은 귀하께서 이 연구 프로젝트에 참여하는 것에 관련된 정보를 모두 이해 및 만족하시고, 연구에 참여하는 것에 동의한다는 것을 의미합니다. 자료는 저와 저의 지도 교수님, 그리고 저의 논문 위원회 위원인 **Dr. Rick Freeze** 교수님과 **Dr. Emily Etcheverry** 교수님과만 공유합니다. 귀하의 정보를

다른 연구자나 스폰서 혹은 관련기관에 공유할 법적 권리가 전혀 없음을 알립니다. 귀하께서 원하신다면, 언제든지 연구에서 빠지실 수 있으며 어떤 질문에 대한 답변도 귀하께서 원하시는 대로 수정이 가능합니다. 귀하의 지속적인 참여는 귀하께서 서명하신 이 동의서에 제시된 바와 같습니다. 그러므로 언제든지 연구의 명확성이나 새로운 정보를 위해 문의해 주시기 바랍니다.

이 연구는 매니토바 대학의 교육/간호 연구 윤리 위원회 (ENREB)에서 연구 진행 허가를 받았습니다. 만약 이 연구에 대해 제안점이나 불만사항이 있으시면, 위의 저의 지도교수님인 Dr. Zana Lutfiyya 에게 [REDACTED] 이나 인간윤리위원회로 [REDACTED] 나 [REDACTED] 로 연락주시기 바랍니다.

앞에서 언급한 바와 같이, 한국어로 결과 요약본이 정리된 문서를 받기를 원하신다면, 이 연구가 완료되는 대로 귀하께 발송해 드릴 것입니다. 발송은 귀하께서 원하시는 방식으로 우편 혹은 이메일로 발송될 것입니다.

궁금한 사항이 있으시면 연락 주시기 바랍니다. 방성휘

전화번호: [REDACTED]

이메일: [REDACTED]

연락 기다리겠습니다.

감사합니다.

방성휘 올림

Japanese Version  
of  
Recruitment Letter  
詳細説明と同意書



日本と韓国で施行されている自閉性児童のための動作法に対するご両親たちの観  
点  
参加者貴下,

私はマニトバ大学の教育学部で博士課程中の房 星輝(バン  
ソフイ)と申します。日本で施行されている自閉性児童のための動作法に対するご  
両親たちの観点を調べるための研究への参加をお願いしたく、この文書を書かせて頂  
きました。

研究題目:

動作法効果:自閉児童の親様の観  
点

研究支援: 個人支援研究; マニトバ大  
学

この同意書,

すなわち参照資料で貴下に提供されるこの文書は研究に対する情報提供過程の一部  
です。貴下にこの研究が何に関する研究なのか,

貴下の参加がどのように参照になるのかに対する基本情報を提示するためです。

もしここに明示されたより詳しい情報、もしくはここに明示されていない情報を望  
まれば、いつでも連絡をください。

この同意書をよくご理解頂けるよう、ご覧になって下さい。

この研究の目的は日本と韓国で施行されている自閉性児童のための動作法に対  
するご両親たちの観点を調べるのにあります。この研究は 1)動作法と自閉の関  
係、動作法が児童たちに及んだ影響、  
2)そして動作法の有効化のための提案に対するご両親たちの意見を調べ、今  
後に役立てようというものです。

研究過程において、参加者に及ぼすいかなる危険要素もありません。何人か  
のご両親たちは自分の経験を振り返りながら興味深い点を見つけることができ  
るでしょう。

この研究のために、最大 1 時間分量の面談形式インタビューに参加する方  
を募集します。少なくとも 1 年間の動作法の経験があるご両親を先着順

10 人に限ってインタビューするでしょう。

お父さんとお母さんお二人様皆参加することも可能です。

日本語のインタビューのために、

参加者の情報に関する秘密保障に同意して署名した通訳が一人参加するでしょう。日本の夏の動作法キャンプにも参加する予定です。したがって、私は福岡、京都、東京、あるいは動作法キャンプでインタビューをすることが可能です。

インタビューは日本語で進行されるでしょう。動作法に対する経験をもとにしたご両親の観点の研究が目的なので

1年以上の動作法の経験があるご両親に限りインタビューをさせて頂きたいと思えます。

日本で施行される自閉性児童のための動作法に関する観点到に係わる質問がインタビューで扱われるでしょう。勿論、

参加する方々は答えられる質問にだけ答えて下さって結構です。また、参加途中で意向にそぐわないと思われる場合はいつでも辞退して頂いて構いません。すべての参加者の匿名性と秘密保障を約束します；

研究途中辞退を希望されれば、参加者の情報は全て削除されます。

参加者が楽に感じることを、またインタビュー内容の秘密維持を考慮して、

私と参加者が皆同意したインタビューの時間と場所を決めるでしょう。

インタビューはデジタル録音機に録音されるでしょう。インタビューの前に、

質問に対する返答を整理する時間を持てるように、日本語で書かれたインタビューの質問誌が電子メールで送られるでしょう。

参加者の匿名性の保護はずっと維持されるでしょう。

参加者の匿名性のために仮名が使われるでしょう。

インタビューの内容は私が文書にし分析するでしょう。

インタビューでされる質問を事前に知っていただくため、インタビューの内容が移して書かれた文書を参加者に発送するでしょう。

この文書はインタビューの資料の分析を始める前に発送されるでしょう。

すべての資料は私を通じて分析されるでしょう。

参加者の実際引用文を使う可能性もあります。参加者の情報の秘密を保護するため、

統合資料のみを報告する予定であり、参加者のお名前は資料のどこにも表記しません。

すべての資料は私の家にある個人用コンピューターにパスワードでザムグムの保存され、どんな機関にも参加者の情報漏洩はされません。

個人の情報の漏洩が生じないように詳らかに検討するでしょう。ただ、私の指導先生、Dr. Zana Lutifiyya だけが資料を閲覧することができます。

もしも参加者の身分を漏洩させる可能性のある資料は資料の分析の時使わないでしょう。資料を通じる研究の結果は私の論文、

また、あるかも知れない発表やジャーナルの掲載のために使われることもあります。

録音されたインタビューとインタビューの内容が移して書かれた文書は私の論文が完了し次第に徹底的に削除されるでしょう。

日本語で書かれた結果の要約本を願ったら、  
この研究が完了し次第に参加者に発送するでしょう。発送の形式は参加者が願う方法で、  
郵便あるいは電子メールでされるでしょう。

この研究は教授/学問研究会議やジャーナル掲載で発表されることもあります。

今後の研究、特に、私の論文、

あるいは追加的な資料のために、今回の研究の後、参加者の方々にはまた意見を求める  
ことがあるかもしれません。そのような時には、

この参加者の方々と一緒に私の研究を続けるため、倫理委員会の承認を再び受けるよう  
にします。また、このことについては、

同意書で参加者の方に、今後の研究のためにまた参加して頂けることが可能であるかを  
質問します。

この文書に署名なされた貴下の署名は、

貴下はこの研究に参加することに係わる情報を皆理解し、満足して、

研究に参加することに同意するというを意味します。

貴下の情報を他の研究者やスポンサーあるいは関連機関に共有することができる法的な  
権利は全くありません。貴下が願ったら、

いつでも研究で抜けることができ、またどんな質問に対する返事も貴下の願う次第に修  
正が可能です。

貴下の持続的な参加は貴下が署名したこの同意書に提示されていることに基づいていま  
す。いつでも研究の明確性や新しい情報のために問い合わせてください。

この研究はマニトバ大学の教育/看護研究倫理委員会

(ENREB)で研究進行許可を受けました。もしこの研究に対する提案や不満事項があれば、

Dr. Zana Lutfiyya の [REDACTED] 上記の連絡先や人間倫理委員会への電話  
お問い合わせメールで ([REDACTED] や [REDACTED]) 連絡ください。

貴下の参照を助けるためにこの同意書の複写本を差し上げます。

房星輝

[REDACTED]

## Appendix C

### Consent Letter



#### **The Effects of Dohsa-hou: Parental Perspectives**

Dear Parents:

First of all, I appreciate your interest in this study. I am a doctoral student from the Faculty of Education at the University of Manitoba. I am inviting you to support for a research study. I am interested in parental perspectives on their experiences with dohsa-hou for their children. I am conducting interviews with parents of children with autism spectrum disorders (ASD). The research project title is "The Effects of Dohsa-hou: Parental Perspectives". The study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba in Canada.

The purpose of this study is to look at how ASD has been understood, responses to ASD, considered from an empirical standpoint and where dohsa-hou fits into these responses. To examine the effects of dohsa-hou approach, I will include your perspectives on dohsa-hou that you have used or received for your child. In this study, I plan on asking you if taking part in dohsa-hou affects the relational behaviours of your child. For example, your perspectives will be sought in order to examine 1) any possible relationships between the approach and their children's such as listening to others, initiating a communication, interacting with others, and participating in tasks and 2) if they think their children's self-awareness of their body image and frame changes during and after dohsa-hou (e.g., posture, movement, and bodily self-awareness).

To help me in this study, I am inviting you to participate in an individual face-to-face interview which should take about 60 minutes of your time. I will stay in the dohsa-hou camp for interviews. I would prefer to have interviews in the camp. The location will be arranged in a private room at the camp site with no supervision. The interviews will be digitally recorded and all data will be stored in my personal computer securely all the time. Korean will be used for interviews in South Korea and Japanese will be used for interviews. An interpreter who signs up on a form to understand and agree to confidentiality of participants will attend only at interviews for Japanese parents. Questions will relate to your perspectives on dohsa-hou for your child: 1) if the parents think the approach as a positive one for their child and 2) how the approach influences the children. I have attached an interview guide. Of course, you will have the right to answer only those questions you feel most comfortable answering, and you can withdraw from this study at any time; should you choose to do so, your data comments will be destroyed.

The data from all of the interviews (whether in Korean or Japanese) will be recorded by a digital

voice recorder, transcribed by me and saved on my personal password protected computer. The secured computer and the digital voice recorder will be with me while I attend the camps and when I travel, and they will be kept in my secured office in my home. As a member checking strategy, I will send the transcribed interview to you. If you want to add, delete or change the information, you may do so. I will use anonyms whenever any name occurs to protect your confidentiality.

Please note that this research is primarily for my thesis dissertation but may be used later should I choose to write further publication on this topic for future journal article submissions. The data will be securely stored in a Zip drive on a password protected computer file as required by the Tri-Council Policy Statement 2 (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). Only I will have access to all of the data. My thesis advisor, Dr. Zana Lutfiyya, will have access to the anonymized data. My thesis committee members, Dr. Rick Freeze, and Dr. Emily Etcheverry, will have access to the anonymized data in the form of summaries and findings from the data. Fieldnotes and transcripts will be written in Korean. The data will be translated in English and anonymized transcripts given to my thesis advisor, Dr. Zana Lutfiyya. Of course, the thesis will be written in English. Any data that are used within my study will be masked and all identifiers stripped from the analysis to ensure anonymity and confidentiality of participants. Only aggregate data will be reported to further ensure the confidentiality of participants. Should any comments potentially identify participants, it will not be used in the analysis. The data will be saved on a personal computer at my home accessible only by me and access will be password protected. All participants will receive a copy of a summary of the results of the study. All the digitally recorded data and transcription will be destroyed when this study is complete. I will keep summaries and findings until my thesis is complete. Once my thesis is complete, I will delete all the digitally recorded voices of interviews, shred and burn any notes from the interviews, erase all written interviews from my personal computer, and double check if I destroy all the data from the digital voice record and my personal computer.

If you indicate that you would like to receive a copy of a summary of the results of the study, you will receive it once the study is complete. This will be sent as the type you want by mail or email.

Again, your participation is voluntary. You are free to withdraw from the study at any time and any data from you will be destroyed on your request. If you do wish to participate, please sign the consent on the bottom of this page. Keep one copy for yourself, and send the second copy to me for my records at the address listed below. If you do not wish to participate, please disregard this information.

Sincerely,  
Seonghwi Bang

[Redacted signature]

E-mail:

Tel:

[Redacted contact information]

The University of Manitoba may look at my research documents in order to make sure that my study is being conducted in an ethical and proper manner. This research has been approved by the Education/Nursing Research Ethics Board (ENREB) If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at [REDACTED], or by e-mail at [REDACTED]. You may also contact my advisor, Dr. Zana Lutfiyya, at [REDACTED].

-----

I have read the consent form and consent to participate in the interview by Seonghwi Bang, a doctoral student at University of Manitoba.

\_\_\_\_\_

Participant's Signature

Date

\_\_\_\_\_

Researcher's Signature

Date

Would you like to receive your interview transcript and a copy of the summary of results?

Yes    No

Email address:

Mail address:

Your interview transcript will be sent to you by October 15, 2015 and the summary of results will be sent to you before December 31, 2015.

Korean  
Version of  
Consent Letter  
상세 설명 및 동의서



동작법 효과: 부모 의견을 바탕으로

참여자 귀하,

매니토바 대학교 교육학부에서 박사과정 중인 방성취입니다. 한국에서 시행되고 있는 자폐 아동을 위한 동작법에 대한 부모님들의 관점을 알아보고자 하는 연구에 참여해 주십사 하고 이렇게 글을 올립니다.

연구 제목: 한국과 일본에서 시행되고 있는 자폐 아동을 위한 동작법에 대한 부모님들의 관점

이 동의서, 즉 참고 자료로 귀하께 제공되는 이 서류는 연구에 대한 정보 제공 과정의 일부입니다. 귀하께 이 연구가 무엇에 관한 연구인지, 귀하의 참여가 어디에 참고가 될 것인지에 대한 기본 정보를 드리고자 합니다. 만약 여기에 명시된 것보다 자세한 정보를 원하시거나, 여기에 명시되어 있지 않은 정보를 원하신다면, 언제든지 문의해 주시기 바랍니다. 이 동의서를 이해하실 수 있도록 자세히 읽어보시길 바랍니다.

이 연구의 목적은 한국과 일본에서 시행되고 있는 자폐 아동을 위한 동작법에 대한 부모님들의 관점을 알아보는 데에 있습니다. 이 연구는 1) 동작법과 자폐의 관계, 동작법이 아동들에게 미친 영향, 2) 그리고 동작법의 유효화를 위한 제안점에 대한 부모님들의 의견을 알아보는 데에 도움이 되리라고 봅니다.

연구 과정 중에 어떤 참가자에게 끼치는 위험 요소는 없습니다. 몇몇 부모님들은 자신의 경험을 되돌아보면서 흥미로운 점을 발견할 수 있을 것입니다.

이 연구를 위해, 최대 1 시간 분량의 면담 형식 인터뷰에 참여하실 분을 모집합니다. 최소 1 년의 동작법 경험이 있으신 부모님을 선착순 10 분에 한하여 인터뷰할 것입니다. 아버님과 어머님 두 분 모두 참여하시는 것도 가능합니다. 저는 서울이나 캠프에서의 인터뷰를 선호하지만, 부모님께서 원하신다면 어느 장소이든 상관없이 방문하여 인터뷰할 수 있습니다. 인터뷰는 한국어로 진행될 것입니다. 한국에서 시행되는 자폐 아동을 위한 동작법에 관한 관점에 관련된 질문들이 인터뷰에서 다루어질 것입니다. 물론, 참가하시는 분들께서는 편하게 느끼시는 질문에만 답하실

수 있는 권리가 있고, 어느 때라도 이 연구에서 빠지실 의향이 있으시다면 빠지실 수 있고; 연구에서 빠지시길 원하신다면, 귀하께서 주신 정보는 모두 삭제될 것입니다.

귀하께서 편하게 느끼시고 인터뷰 내용의 비밀 유지를 위해 저와 귀하께서 모두 동의한 인터뷰 시각과 장소를 정할 것입니다. 인터뷰는 디지털 녹음기로 녹음될 것입니다. 인터뷰에 앞서 질문에 대한 답변을 생각하고 정리하실 시간을 위한 한국어로 된 인터뷰 질문지가 이메일을 통해 발송될 것입니다. 귀하의 익명성 보호는 계속 유지될 것입니다. 귀하의 익명성을 위해 가명이 사용될 것입니다. 귀하의 인터뷰 내용은 저를 통해서만 문서에 옮겨지고 분석될 것입니다. 답변 내용을 귀하께서 추가, 삭제, 혹은 변경하실 수 있도록 하고 빠진 부분이 없는지 확인하기 위해, 귀하의 인터뷰 내용이 옮겨 적힌 문서를 보내드릴 것입니다. 이 문서는 인터뷰 자료 분석을 시작하기 전에 발송될 것입니다. 이 연구를 위한 자료는 저를 통해서만 분석될 것입니다. 귀하의 인용문을 직접 사용할 수도 있습니다. 귀하의 참여 비밀보장을 위해 통합 자료만이 발표될 것이며, 귀하의 성함은 자료의 어디에도 표기되지 않을 것입니다. 모든 자료는 저의 집에 있는 개인 컴퓨터에 비밀번호로 잠금 저장될 것이며, 어떠한 기관에게도 신분 정보 노출을 하지 않을 것입니다. 개인정보 노출이 생기지 않도록 꼼꼼히 검토될 것입니다. 단, 저의 지도교수님, **Dr. Zana Lutfiyya** 만이 자료를 열람할 것입니다. 혹시라도 귀하의 신분을 노출시킬 만한 자료는 자료 분석시 사용되지 않을 것입니다. 자료를 통한 연구 결과는 저의 논문, 혹시 있을지 모를 발표나 저널 게재를 위해 사용될 수도 있습니다. 녹음된 인터뷰와 그 내용이 옮겨 적힌 문서는 저의 논문이 완료되는 대로 철저히 삭제될 것입니다.

한국어로 결과 요약본이 정리된 문서를 받기를 원하신다면, 이 연구가 완료되는 대로 귀하께 발송해 드릴 것입니다. 발송은 귀하께서 원하시는 방식으로 우편 혹은 이메일로 발송될 것입니다. 이 연구는 교수/학문연구회이나 저널 게재에서 발표될 수도 있습니다.

추후 연구, 확실히 말해서, 저의 추후 논문이나 추가 자료를 위해 귀하에게 다시 협조 요청을 할 수도 있습니다. 만약 이 일이 생길 시, 여러분과 함께 저의 연구를 계속하기 위한 윤리 위원회의 승인을 다시 받도록 할 것입니다. 그에 더하여, 동의서를 통해 여러분께서 추후 연구를 위해 다시 참여할 의사가 있는지 여쭙겠습니다.

이 서류에 서명하신 귀하의 사인은 귀하께서 이 연구 프로젝트에 참여하는 것에 관련된 정보를 모두 이해 및 만족하시고, 연구에 참여하는 것에 동의한다는 것을 의미합니다. 자료는 저와 저의 지도 교수님, 그리고 저의 논문 위원회 위원인 **Dr. Rick Freeze** 교수님과 **Dr. Emily Etcheverry** 교수님과만 공유합니다. 귀하의 정보를 다른 연구자나 스폰서 혹은 관련기관에 공유할 법적 권리가 전혀 없음을 알립니다.

귀하께서 원하신다면, 언제든지 연구에서 빠지실 수 있으며 어떤 질문에 대한 답변도 귀하께서 원하시는 대로 수정이 가능합니다. 귀하의 지속적인 참여는 귀하께서 서명하신 이 동의서에 제시된 바와 같습니다. 그러므로 언제든지 연구의 명확성이나 새로운 정보를 위해 문의해 주시기 바랍니다.

방성휘

[Redacted]

이메일

전화번호:

이 연구는 매니토바 대학의 교육/간호 연구 윤리 위원회 (ENREB)에서 연구 진행 허가를 받았습니다. 만약 이 연구에 대해 제안점이나 불만사항이 있으시면, 위의 저의 지도교수님인 Dr. Zana Lutfiyya 에게 [Redacted] 이나 인간윤리위원회로 [Redacted] 나 [Redacted] 연락주시기 바랍니다.

앞에서 언급한 바와 같이, 한국어로 결과 요약본이 정리된 문서를 받기를 원하신다면, 이 연구가 완료되는 대로 귀하께 발송해 드릴 것입니다. 발송은 귀하께서 원하시는 방식으로 우편 혹은 이메일로 발송될 것입니다.

\_\_\_\_\_  
참여자 서명

\_\_\_\_\_  
날짜

\_\_\_\_\_  
연구자 서명

\_\_\_\_\_  
날짜

결과 요약본을 받기를 원하십니까? 예:

아니오:

이메일 주소:

우편 주소:

인터뷰 내용은 2015년 10월 15일 보내 드리겠고 내용의 요약본은 2015년 12월 31일 전에 받아 보실 수 있도록 하겠습니다.

Japanese Version  
of  
Consent Letter  
詳細説明と同意書



"動作法効果:自閉児童の親様の観点"

参加者貴下,

私はマニトバ大学の教育学部で博士課程中の房 星輝(バンソソフィ)と申します。日本で施行されている自閉性児童のための動作法に対するご両親たちの観点を調べるための研究への参加をお願いしたく、この文書を書かせて頂きました。.

研究題目:

日本と韓国で施行されている自閉性児童のための動作法に対するご両親たちの観点

研究支援: 個人支援研究; マニトバ大学

この同意書,

すなわち参照資料で貴下に提供されるこの文書は研究に対する情報提供過程の一部です。貴下にこの研究が何に關する研究なのか,

貴下の参加がどのように参照になるのかに対する基本情報を提示するためです。

もしここに明示されたより詳しい情報,もしくはここに明示されていない情報を望まれば,いつでも連絡をください。

この同意書をよくご理解頂けるよう、ご覧になって下さい。.

この研究の目的は日本と韓国で施行されている自閉性児童のための動作法に対するご両親たちの観点を調べるのにあります。この研究は 1)動作法と自閉の關係,

動作法が児童たちに及んだ影響,

2)そして動作法の有効化のための提案に対するご両親たちの意見を調べ、今後役に立てようというものです。.

研究過程において、参加者に及ぼすいかなる危険要素もありません。何人かのご両親たちは自分の経験を振り返りながら興味深い点を見つけることができるでしょう。

この研究のために、最大1時間分量の面談形式インタビューに参加する方を募集します。

少なくとも1年間の動作法の経験があるご両親を先着順

10人に限ってインタビューするでしょう。

お父さんとお母さんお二人様皆参加することも可能です。

日本語のインタビューのために、  
参加者の情報に関する秘密保障に同意して署名した通訳が一人参加するでしょう。日本の夏の動作法キャンプにも参加する予定です。したがって、私は福岡、京都、東京、あるいは動作法キャンプでインタビューをすることが可能です。

インタビューは日本語で進行されるでしょう。動作法に対する経験をもとにしたご両親の観点の研究が目的なので

1年以上の動作法の経験があるご両親に限りインタビューをさせて頂きたいと思えます。

日本で施行される自閉性児童のための動作法に関する観点に係わる質問がインタビューで扱われるでしょう。勿論、

参加する方々は答えられる質問にだけ答えて下さって結構です。また、参加途中で意向にそぐわないと思われる場合はいつでも辞退して頂いて構いません。すべての参加者の匿名性と秘密保障を約束します；

研究途中辞退を希望されれば、参加者の情報は全て削除されます。

参加者が楽に感じることを、またインタビュー内容の秘密維持を考慮して、

私と参加者が皆同意したインタビューの時間と場所を決めるでしょう。

インタビューはデジタル録音機に録音されるでしょう。インタビューの前に、

質問に対する返答を整理する時間を持てるように、日本語で書かれたインタビューの質問誌が電子メールで送られるでしょう。

参加者の匿名性の保護はずっと維持されるでしょう。

参加者の匿名性のために仮名が使われるでしょう。

インタビューの内容は私が文書にし分析するでしょう。

インタビューでされる質問を事前に知っていただくため、インタビューの内容が移して書かれた文書を参加者に発送するでしょう。

この文書はインタビューの資料の分析を始める前に発送されるでしょう。

すべての資料は私を通じて分析されるでしょう。

参加者の実際引用文を使う可能性もあります。参加者の情報の秘密を保護するため、

統合資料のみを報告する予定であり、参加者のお名前は資料のどこにも表記しません。

すべての資料は私の家にある個人用コンピューターにパスワードでザムグムの保存され、どんな機関にも参加者の情報漏洩はされません。

個人の情報の漏洩が生じないように詳らかに検討するでしょう。ただ、私の指導先生、Dr. Zana Lutifiyya だけが資料を閲覧することができます。

もしも参加者の身分を漏洩させる可能性のある資料は資料の分析の時使わないでしょう。資料を通じる研究の結果は私の論文、

また、あるかも知れない発表やジャーナルの掲載のために使われることもあります。

録音されたインタビューとインタビューの内容が移して書かれた文書は私の論文が完了し次第に徹底的に削除されるでしょう。

日本語で書かれた結果の要約本を願ったら、

この研究が完了し次第に参加者に発送するでしょう。発送の形式は参加者が願う方法で、郵便あるいは電子メールでされるでしょう。

この研究は教授/学問研究会議やジャーナル掲載で発表されることもあります。

今後の研究, 特に, 私の論文,

あるいは追加的な資料のために、今回の研究の後、参加者の方々にはまた意見を求めることがあるかもしれません。そのような時には、

この参加者の方々と一緒に私の研究を続けるため、倫理委員会の承認を再び受けるようにします。また、このことについては、

同意書で参加者の方に、今後の研究のためにまた参加して頂けることが可能であるかを質問します。

この文書に署名なされた貴下の署名は、

貴下はこの研究に参加することに係わる情報を皆理解し、満足して、研究に参加することに同意するということを意味します。

貴下の情報を他の研究者やスポンサーあるいは関連機関に共有することができる法的な権利は全くありません。貴下が願ったら、

いつでも研究で抜けることができ、またどんな質問に対する返事も貴下の願い次第に修正が可能です。

貴下の持続的な参加は貴下が署名したこの同意書に提示されていることに基づいています。いつでも研究の明確性や新しい情報のために問い合わせてください。

この研究はマニトバ大学の教育/看護研究倫理委員会

(ENREB)で研究進行許可を受けました。もしこの研究に対する提案や不満事項があれば、

Dr. Zana Lutfiyya の [REDACTED] 上記の連絡先や人間倫理委員会への電話お問い合わせメールで ([REDACTED]) 連絡ください。

---

参加者署名 日付

---

研究者署名 日付

貴下の参照を助けるためにこの同意書の複写本を差し上げます。

前と言及したところのように、日本語で書かれた結果の要約本を願ったら、

この研究が完了し次第に参加者に発送するでしょう。発送の形式は参加者が願う方法で、郵便あるいは電子メールでされるでしょう。

結果の要約本を受けるのを願いますか? はい:      いいえ:

電子メール住所:

郵便住所:

## Appendix D

### Interview Guide

This interview is to examine the perspectives of parents regarding the effectiveness of dohsa-hou for their children with Autism Spectrum Disorder (ASD). The research project title is "The Effects of Dohsa-hou: Parental Perspectives". The purpose of this study is to look at how ASD has been understood, responses to ASD, considered from an empirical standpoint and where dohsa-hou fits into these responses. To examine the effects of dohsa-hou approach, I will include your perspectives on dohsa-hou that you have used or received for your child. In this study, I plan on asking you if taking part in dohsa-hou affects the relational behaviours of your child. For example, your perspectives will be sought in order to examine 1) any possible relationships between the approach and their children's such as listening to others, initiating a communication, interacting with others, and participating in tasks and 2) if they think their children's self-awareness of their body image and frame changes during and after dohsa-hou (e.g., posture, movement, and bodily self-awareness).

#### Section 1: Background

1. What are your child's experiences at home, at school and in the larger community like? What are the facilitators or your child's participation at home, school, and in the larger community? Any barriers?  
Probes: Could you give me an example of it? What do you mean by that? Could you tell me more?
2. How did you and your child get involved in the dohsa-hou approach?  
Probes: How did you hear about it? When did you start to use it?
3. Describe your child's current involvement with dohsa-hou.  
Probes: How often? Who does it? How long?

#### Section 2: Perspectives on their experiences

4. Have you noticed anything since your child began dohsa-hou? If so, what?  
Probes: Could you give me an example of it? What do you mean by that? Could you tell me more on the changes of your child? Why do you think it was successful/ unsuccessful for your child?
5. One purpose of dohsa-hou is to help a child develop greater self-awareness of how her/his body moves and her/his body image when s/he receives dohsa-hou or you use dohsa-hou with your child. What, if anything, have you seen regarding self-awareness since your child started dohsa-hou?  
Probes: How do you understand self-awareness? Could you give me an example of it? What do you mean by that? Could you tell me more? Why do you think it was successful/ unsuccessful?
6. Another purpose of dohsa-hou is to help a child develop his/her ability to communicate and relate to others. What, if anything, have you seen regarding communication and relational behaviours since your child started dohsa-hou?
7. What are the facilitators and barriers to using the approach? What do you feel about using the approach for your child?  
Probes: Could you give me an example? What do you mean by that? Could you tell me more?
8. Have I missed anything? Do you have anything else you want to say?

Korean Version  
of  
Interview Guide  
인터뷰 가이드

이 연구는 한국과 일본에서 시행되고 있는 자폐성 아동들을 위한 동작법에 대한 생각에 중점을 두고 있습니다. 이 연구의 제목은 '한국과 일본에서 시행되는 자폐성 아동들을 위한 동작법에 대한 부모님들의 관점'입니다. 이 인터뷰 가이드는 실제 인터뷰에서 쓰여질 것입니다. 귀하께서 편하게 답하실 수 있는 질문에만 답하셔도 됩니다. 이 연구는 1) 자폐 아동들을 위한 동작법을 검토하고, 어떻게 영향을 끼치는지, 2) 그리고 어떤 제안점이 제시될 수 있는지를 알아보기 위함입니다. 다음의 질문에 답하여 서술해 주시기 바랍니다. 이 인터뷰는 면담 형식으로 이루어질 것입니다.

**Section 1: 배경**

1. 학교, 가정, 지역사회에서 자녀가 어떤 경험을 하고 있는 얘기해 주십시오. 학교, 가정, 지역사회에서 자녀에게 도움이 되는 것과 방해가 되는 것은 무엇입니까?  
Probes: 예를 들면? 무슨 의미이신가요? 부가설명을 하신다면요?
2. 동작법은 어떻게 시작하셨나요?  
Probes: 어떻게 들으셨나요? 언제 시작하셨나요?
3. 최근 동작법을 어떻게 사용하고 있는지 말씀해 주십시오.  
Probes: 얼마나 자주? 누가? 얼마나 오래?

**Section 2: 이용 후기**

4. 동작법 시행 이후 뭔가 달라진 점을 발견 하셨나요? 그렇다면, 무엇인가요?  
Probes: 예를 든다면? 무슨 의미이신가요? 부가 설명을 하신다면? 왜 동작법이 성공적/비성공적이라 생각하십니까?
5. 동작법의 목적 중 하나가 바로 아동의 자기 신체 움직임과 신체 명칭 이해를 돕는 것이지요.  
Probes: 자기 이해가 무엇이라고 생각하십니까? 예를 들면요? 무슨 의미이신가요? 좀더 말씀해 주세요. 왜 성공적/비성공적이라 생각하십니까?
6. 동작법의 또다른 목적이 바로 아동이 다른 사람들과 의사소통 하는 데에 도움이 되게 하는 것인데요. 있다면, 무엇입니까?
7. 동작법 사용에 있어서 도움이 되는 것 혹은 방해가 되는 것은? 동작법 이용에 대해 어떻게 느끼고 계십니까?  
Probes: 예를 들면? 무슨 의미입니까? 부연 설명을 하신다면?
8. 놓친 것이 있는지요? 덧붙이실 말씀 있습니까?

Japanese Version  
of  
Interview Guide  
インタビューガイド

この研究は日本と韓国で施行されている自閉性児童たちのための動作法に対する考えに重点を置いています。この研究の題目は'日本と韓国で施行される自閉性児童たちのための動作法に対するご両親たちの観点'です。

このインタビューガイドは**実際**インタビューで使われるでしょう。あなたが返事することができる質問にだけ返事して下さい。結構です。

この研究は自閉性児童たちのための動作法を**検討**して、どんな影響を及ぼすのか、そしてどんな提案が提示されることが出来るかを調べるためのものです。

次の質問に答えて叙述してください。このインタビューは面談の形式で行われます。

### Section 1: 背景

1. 学校、家庭、地域社会での子息がどのような**経験**をしている話してください。  
学校、家庭、地域社会で子供の役に立つことと妨害となるのは何ですか？

Probes: 例えば? 何の意味でしょうか? 追加**説明**をしたら?

2. 動作法はどのように始めたのですか?

Probes: どう聞かれましたか。いつ始めたのですか?

3. 動作法**対して**ご存じなことをおっしゃっていただけますか?

Probes: どれくらい頻繁に? 誰が? どのくらい?

### Section 2: 利用後期

4. 動作法施行以降、何か**変わった**ことを**発見**しましたか? それなら、何ですか。

Probes: 例をあげれば? 何の意味でしょうか? 追加**説明**をしたら?

どうして動作法が**成功的/ビソン公的**と思いますか?

5. 動作法を通じてどんな**効果**を期待しましたか?

Probes: 自分と利害が何だと思いますか。たとえば? 何の意味でしょうか?

もう少しおっしゃってください。どうして**成功的/ビソン公的**と思いますか?

6. 動作法のもう一つの**目的**がすぐに児童が他の人と意思疎通するのに役立つようにすることです。いたら、何ですか?

7. 動作法を受けながら**問題点**や**心配事項**がありますか?

Probes: 例えば? どういう意味ですか? **説明**をしたら?

8. 他に何か**教えて**頂けることはありますか?

**Appendix E**  
Confidentiality Consent of Interpreter

The Effects of Dohsa-hou: Parental Perspectives

Note: This will be translated in Japanese to be given to an interpreter and shown to Japanese parents.

As an interpreter Japanese to Korean/Korean to Japanese of interviews, transcriptions and letters to parents and a president of the OOOOOOOOOOOOOOOO for the study, it is important that you understand and comply with confidentiality. Therefore, please read and consider carefully the following.

Personal and confidential matters pertaining to the interviews, its participants, interpreter and researcher shall ONLY be discussed during the interviews. As an interpreter, you must limit your discussion to the interviews. Interpreter is not to release or cause to be released any information regarding the nature of the participants. An interpreter will be expected to sign this form before the interviews of the study.

I, \_\_\_\_\_, have read, understand and agree to comply with the contents of the confidentiality of the participants. I promise not to release any information from the interviews. I understand their confidentiality continues.

\_\_\_\_\_  
Interpreter's Signature:

\_\_\_\_\_  
Date:

\_\_\_\_\_  
Print name:

Please sign and return to the researcher. Retain a copy for you. It might be shown to Japanese parents if the parents want to see your signed consent.

Japanese Version  
of  
Confidentiality Consent of Interpreter  
秘密保障同意書

動作法の効果: 両親の観点

この研究のための日本人ご両親たちのインタビューのために日本語を韓国語に/韓国語を日本語に通訳する通訳士として、すべての情報に対する秘密保障を理解して同意することは重要な事項です。下の内容を必ず読んでください。

個人情報の保護のため、参加者、通訳、そして研究者は実際のインタビューでのみ、インタビュー質問に対する内容を話すことができる。通訳として、あなたは必ずあなたの意見を言うことを制限しなければならない。通訳は参加者の情報を漏出する、または漏出しうる要因を作ってはいけない。通訳は五人の日本人ご両親のインタビューが始まる前にこの書類に署名してください。

私は、\_\_\_\_\_, このインタビューの参加者の秘密保障に対する内容を読み、理解して、同意します。私は五つのインタビューからのどんな情報も漏らしません。私はこの秘密保障をずっと守ることを約束します。

署名:                      日付:

お名前:

署名した後にこの研究者に提出してください。複写本を持ってください。もしご両親が願ったら、あなたの署名した同意書をご両親に見て頂くことがあります。

## Appendix F



Research Ethics and Compliance  
Office of the Vice-President (Research and International)

Human Ethics  
208-194 Dafoe Road  
Winnipeg, MB  
Canada R3T 2N2  
Phone +204-474-7122  
Fax +204-269-7173

## APPROVAL CERTIFICATE

September 22, 2015

**TO:** Seonghwi Bang (Advisor Z. Lutfiyya)  
Principal Investigator [REDACTED]

**FROM:** Thomas Falkenberg, Chair  
Education/Nursing Research Ethics Board (ENREB)

**Re:** Protocol #E2015:077  
"The Effects of Dohsa-hou: Parental Perspectives"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

**The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/orec/ethics/human\\_ethics\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.**

## Appendix G



Research Ethics and Compliance  
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### RENEWAL APPROVAL

August 18, 2016

**TO:** Seonghwi Bang (Supervisors: Zana Lutfiyya)  
Principal Investigator

**FROM:** Sarah Teetzel, Vice Chair  
Education/Nursing Research Ethics Board (ENREB)

**Re:** Protocol #E2015:077 (HS18765)  
"The Effects of Dohsa-hou: Parental Perspectives"

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Please be advised that your above-referenced protocol has received approval for renewal by the Education/Nursing Research Ethics Board. **This approval is valid for one year and will expire on September 21, 2017.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Coordinator in advance of implementation of such changes.