

APPLIED BEHAVIOUR ANALYSIS IN TAIWAN: EXAMINING HOW PARENTS OF
CHILDREN WITH AUTISM PERCEIVE AND SELECT INTERVENTION OPTIONS

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Abstract

Although many different types of autism treatments exist, very few are grounded in evidence. Interventions based on applied behaviour analysis (ABA) have received substantial evidence supporting their efficacy and community effectiveness and are considered to be best practice for children with autism. Despite this, a gap exists in the implementation and usage of these services in many parts of the world, including Taiwan. Through a mixed methods research design consisting of two phases, this dissertation explored factors that contribute to the selection or avoidance of ABA-based intervention. In phase 1, a survey methodology was used to examine the knowledge and attitudes about autism and ABA-based services, as well as to explore the service utilization patterns of parents of children with autism in Taiwan. In phase 2, semi-structured interviews were conducted with key informants (i.e., parents who had previously selected or were currently using ABA-based interventions, educators and ABA service providers) to clarify and elaborate on the quantitative results obtained in phase 1. The findings from this dissertation indicate that level of knowledge about ABA was significantly related to the selection of ABA-based services, over and above other parent characteristics (i.e., parent attitudes toward ABA and parent knowledge about autism) and child characteristics (i.e., autism severity, maladaptive behaviour, adaptive behaviour, and diagnostic status). Specific factors contributing to this knowledge gap were identified at the parent level, at the intervention level, and at the systems level. The clinical and policy implications are described in this dissertation with respect to each of the barriers identified.

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List of Abbreviations

ABA	Applied Behaviour Analysis
BACB	Behaviour Analyst Certification Board
CAM	Complementary and alternative medicine
HBM	Health Belief Model
WHO	World Health Organization

Chapter 1: Introduction

Autism, or autism spectrum disorder, is a lifelong disorder in which individuals have varying levels of impairment. The two core features of autism are 1) deficits in social communication and social interaction and 2) the presence of restrictive and repetitive interests and/or behaviours (American Psychiatric Association, 2013). An overwhelming number of interventions for autism exist, however, only a small subset of these interventions is grounded in research. For parents, the selection of interventions for their child is one of the first decisions they must make following their child's diagnosis and studies have found that some parents engage in interventions that are ineffective, lack evidence, or are even harmful (Green et al., 2006). Of all the autism intervention options available, it is clear that those based on applied behaviour analysis (ABA) have had the most extensive body of literature supporting their effectiveness in improving children's outcomes (National Autism Center, 2009, 2015). As a result, most Canadian provinces provide some support for ABA-based services for children with autism, and these services are often endorsed and available (even if only privately) in virtually all Western countries. Despite the literature supporting the effectiveness of ABA-based treatment in children with autism, and the prevalence of ABA-based treatment in many western countries, there is a noticeable gap in the usage and availability of these services in other countries such as Taiwan. Therefore, the main objective of this dissertation was to explore factors contributing to the implementation gap of ABA-based services in Taiwan. A better understanding of how parents in Taiwan perceive autism itself and ABA-based treatments may help inform future public health policy to address barriers that exist for parents.

Using a mixed-methods design, this research project was comprised of a quantitative phase followed by a qualitative phase. This paper has been organized into four chapters,

including this introductory chapter, which provides the background on the current research project by first describing the characteristics of autism and the cultural context of Taiwan. Next, the types of autism treatments available are discussed, followed by a review of the literature related to ABA-based intervention as well as a review of the factors contributing to the implementation gap. Following this background, the remaining part of this chapter provides an overview of the overall project design. In chapters 2 and 3, the methodology, analyses, and discussion from the quantitative phase and qualitative phase respectively are presented. In chapter four, an overarching discussion integrating the findings from both phases is provided, and the implications of these findings for future research and clinical practice are presented. Limitations and conclusions of the study are then provided.

Autism

Autism is an early onset neurodevelopmental disorder, with a wide range of symptom presentation and severity (American Psychiatric Association, 2013). Conditions previously known as autistic disorder, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified, have now been collapsed into the diagnostic label of autism spectrum disorder (American Psychiatric Association, 2013). Different terms (i.e., autistic people, on the autism spectrum, autism spectrum disorder) have also been used to describe autism (Kenny et al., 2016), and for the purposes of this paper, the term autism will be used. In addition to the core symptoms of autism, individuals have varying degrees of cognitive, adaptive, and maladaptive functioning which impact both the individual's and family's quality of life and may require intervention (Hartley et al., 2008; Hill et al., 2014; Kanne & Mazurek, 2011). Research suggests that autism is a result of both genetic and environmental causes, however the specific mechanisms are not well understood (Bölte et al.,

2019). The global prevalence rate of autism based on data from 1990 to 2010 is estimated to be one in 132 individuals (Baxter et al., 2014).

Understanding Autism within the Taiwan Cultural and Societal Context

Although the prevalence and main traits of autism are similar across cultures, the interpretation of how these traits affect the child, the family, and society, is experienced differently based on the cultural lens through which the disorder is seen. Cultural factors influence every aspect of the autism diagnosis, such as the perceived seriousness of the disorder, its etiology, the diagnostic journey, and the types of treatment or intervention services selected (Daley, 2002; Ravindran & Myers, 2012). Taiwan is deeply rooted in traditional Chinese culture and Confucian values (Kang et al., 2002). As with many East Asian countries, Taiwan society places a heavy emphasis on education and obedience. For children with special needs who have difficulty with learning and behavioural challenges however, these East Asian values may contribute to stigma and negative attitudes towards the child and their family (Wang et al., 2013). Within the Chinese culture, it is believed that one's current fate is a result of the actions of one's ancestors (Kang et al., 2002). Consequently, many parents believe that having a child with special needs is a punishment for sins from an earlier life, which results in feelings of guilt and shame. Often, this prevents parents from seeking help outside of the family or disclosing the diagnosis to others (Wang et al., 2013). This reticence may also explain why there is a lack of published research in general within the field of special needs, why there is a lack of understanding about autism (Chen et al., 2015; Hsu et al., 2017; Shyu et al., 2010), and also why there is a paucity of appropriate services, such as ABA-based intervention, in Taiwan.

In terms of the autism diagnostic and treatment pathway in Taiwan, the diagnosis of autism can be done by medical doctors only, and more specifically, only a psychiatrist has the authority

to issue a disability identification card which provides access to services funded by the National Health Insurance. This program provides comprehensive medical care coverage with minimal cost sharing and it is estimated that 99% of all Taiwanese citizen are covered under this program (Wu et al., 2010). Under the publicly funded healthcare system, physical therapy, occupational, speech therapy as well as other types of treatments (e.g., social skills groups, psychological services) are typically offered for young children prior to entering the school system. Once the child reaches school-age and meets the requirements set by the *Committee responsible for identification and placement of gifted and disabled students*, children are eligible to receive speech, occupational, and physical therapy services covered by Ministry of Education throughout their schooling until college. However, since resources are limited, children spend a lengthy time waiting for these services and parents often resort to alternative treatments.

Types of Autism Treatment

Treatments for autism can be categorized as biological (e.g., medication, vitamins, diets) or non-biological (e.g., behavioural intervention, sensory integration) and fall on a continuum of empirical support, with ABA-based interventions receiving the largest amount of research support for effectiveness. There have been at least 111 different treatments identified for autism (Green et al., 2006). Commonly used conventional treatments based on Western samples, include speech therapy, occupational therapy, and ABA-based intervention (Green et al., 2006), as well as complementary and alternative medicine (CAM). CAM is an umbrella term which encompasses an array of practices and ideas outside the realm of conventional medicine in a particular society or culture (O'Connor et al., 1997) and often have a weak or nonexistent evidence base and may have side effects (Levy & Hyman, 2008). In a recent large-scale study ($n = 1084$) conducted in the US, 88% of parents reported either recent or current CAM usage, CAM

products (e.g., melatonin, vitamin B12, probiotics) being the most popular form of CAM used (Owen-Smith et al., 2015). In East Asian countries however, Traditional Chinese Medicine is a common type of CAM, and includes the use of acupuncture, Tuina, moxibustion, and herbal medicine. With a history spanning 2000 years and originating in China, Traditional Chinese Medicine was the main form of medical treatment in China prior to the introduction of Western medicine in the last century. As a result, both of these medical models now co-exist in many Chinese societies, such as in Hong Kong and in Taiwan. In a Hong Kong study of 98 parents of children with autism, it was found that 41% used CAM treatments, and that the use of acupuncture was the most common form of CAM used (Wong, 2009). Similar to Hong Kong where both Western and Eastern treatment options exist, this could potentially make the selection of evidence-based autism treatments even more complex and difficult for parents in Taiwan.

Evidence-Based Treatment: Applied Behaviour Analysis

Of all the autism treatments, interventions based on ABA principles represent the largest category of established interventions for individuals with autism (e.g., National Autism Center, 2009, 2015; Odom et al., 2010; Steinbrenner et al., 2020; Wong et al., 2015). ABA is a science that uses tactics based on the principles of behaviour to improve socially significant behaviours (Cooper et al., 2020). For an intervention to be considered ABA, it must have the seven core dimensions as defined in detail in the seminal paper by Baer et al. (1968): Applied, Behavioural, Analytical, Technological, Conceptually systematic, Effective, and Generality. An ABA framework can be applied to a range of behaviours and with different individuals, across a range of ages and diagnoses. For the purposes of this paper, the term ‘ABA-based’ will be used to encompass treatments, services, and interventions that incorporate the seven core dimensions described previously and utilize procedures derived from the science of behaviour.

For individuals with autism specifically, ABA-based interventions can be categorized into either focused or comprehensive interventions (The Ontario Association for Behaviour Analysis, 2017). Focused interventions target the development of specific skills (e.g., using the toilet, imitation skills, academic skills) and/or address specific behavioural issues (e.g., self-injurious behaviours, stereotypical behaviours). Focused interventions can be used with individuals of any age and vary in the intensity (number of intervention hours per week) and duration. Intervention typically terminates when the pre-defined target is achieved. For instance, a focused intervention may use behavioural chaining to teach toileting or direct instruction to teach math skills. In contrast, comprehensive intervention is distinguished from other types of ABA therapy because it targets multiple goals and is implemented intensively (occurring many hours per week for a prolonged period). Intensive Behavioural Intervention is a specific type of comprehensive ABA intervention designed for young children with autism (i.e., preschool age) and is intensive in nature (i.e., 20-40 hours a week for one to two years) (Perry et al., 2016).

Research on focused ABA-based interventions began in the 1950s and Wolf et al. (1963) was one of the first to use focused interventions with a young child with autism. Since then, focused ABA-based interventions such as discrete trial training, prompting, differential reinforcement, and video modeling have had numerous high-quality studies supporting their effectiveness and are considered to be evidence-based practices for children and youth with autism based on several large scale reviews and consensus documents (e.g., National Autism Center, 2009, 2015; Odom et al., 2010; Steinbrenner et al., 2020; Wong et al., 2015).

In terms of comprehensive interventions, the effectiveness of intensive behavioural intervention in very young children with autism was convincingly demonstrated by Lovaas' (1987) study, which found large IQ changes in 47% of young children with autism who received

ABA-based intervention for 40 or more hours a week for 2 or more years, versus 10 hours or less in a matched control group. Some of the children in Lovaas' treatment group improved enough to no longer meet criteria for autism. In the 30 years since this seminal study, other studies have also reported similar findings (Cohen et al., 2006; Howard et al., 2014; Sallows & Graupner, 2005), with intensive behavioural intervention showing superior results (typically significant gains in cognitive ability and adaptive behaviour) compared to treatment-as-usual, special education, and equally intensive autism-specific special education. In the few follow-up studies that have been conducted, these positive outcomes are also shown to be maintained even long after intensive behavioural intervention treatment has ended (McEachin et al., 1993; Perry et al., 2017). Research about specific child and treatment characteristics that lead to best outcomes has suggested that children who have relatively higher cognitive ability (Remington et al., 2007) and who are younger at the start of treatment (Eldevik et al., 2012; Goin-Kochel et al., 2007; Harris & Handleman, 2000; Perry et al., 2013), as well as children who receive a larger dosage of the treatment (Eikeseth et al., 2002; Granpeesheh et al., 2011; Luiselli et al., 2000; T. Smith et al., 2000) achieve better outcomes.

ABA-based Treatment Implementation Gap

Despite the evidence base for ABA-based treatment, however, the implementation of these services in community settings has been met with differing levels of success (Keenan et al., 2015; Roll-Pettersson et al., 2016). It is often difficult for interventions to be transported from highly controlled research settings to community settings as contextual variables such as financial resources, training and supervision, and acceptability of the intervention, affect the community implementation (Odom et al., 2019). For some countries, such as Canada and the U.S., ABA-based interventions have been readily adopted and included as part of the national

recommendation for children with autism (Autism Society Canada, 2018; National Autism Center, 2015a; U.S. Department of Health and Human Services, 1999). On the other hand, Taiwan with a population of 23.6 million people, has only a few centers and programs providing ABA-based intervention. Unlike speech and occupational therapists in Taiwan, there are no degree courses that lead to a degree in ABA and ABA-based service providers are not recognized as healthcare professionals. Although Taiwan has some approved courses from the Behaviour Analyst Certification Board (BACB), which is a U.S. non-profit corporation providing professional credentialing internationally to individuals in the field of ABA up until the year 2020 (BACB, 2020a), only 39 individuals in Taiwan currently hold a BACB credential (BACB, 2020b).

Although it is evident that a large research-to-practice gap exists in Taiwan, it is unclear what has contributed to this gap. One explanation for this implementation gap may be due to parent decision-making factors. The literature on autism treatments suggest that parents select treatments based on a wide range of factors (as discussed in detail below), but there has been little agreement on which specific factors affect which treatment choices (Wilson et al., 2018). Part of the reason for this is that much of the current research (Al Anbar et al., 2010; Dardennes et al., 2011; Mire et al., 2017) has focused on examining predictors for general treatment categories (i.e., predicting the use of “educative” treatments which include both ABA-based and non-ABA-based interventions), rather than predictors for the selection of one specific type of treatment (i.e., ABA intervention). The current literature also heavily focuses on the predictors of selecting CAM treatments, which are linked to potentially harmful side effects, rather than the predictors of the selection of evidence-based treatments (Wilson et al., 2018). On the other hand, the predictors of evidence-based treatment selection have been explored only minimally. So far,

the current literature suggests that parent treatment decision-making is based on a variety of child, parent, and intervention factors.

Child Factors

In terms of child factors, some studies have suggested that parents of younger children and children who have more severe autistic symptoms are more likely to use ABA-based intervention, however this research is limited in important ways (Bowker et al., 2011; Green et al., 2006). First, these studies were conducted using large online surveys with mainly Western samples, and it is unknown whether these findings can be generalized to regions with a Chinese cultural background. Secondly, both Bowker et al. (2011) and Green et al. (2006) assessed autism severity through parent reported diagnostic information, and the diagnosis was not confirmed nor validated with objective measures. For instance, in the study by Green and colleagues (2006), parents were asked to indicate the type and severity of their child's autism (i.e., Asperger's syndrome, mild autism, or severe autism). Similarly, in the study by Bowker et al. (2011), the severity of autism symptoms was inferred based on the type of diagnosis the parents reported (i.e., Asperger's, PDD-NOS, or autistic). In the study by Shepherd et al. (2018), authors used a validated measure, the Autism Impact Measure (Kanne et al., 2014), to examine the specific core autism symptoms that predicted the use of autism interventions in New Zealand. The results of the study showed that parents who rated their child with more restricted and ritualized behaviours, more impairment in communication, and with a higher presence of odd and atypical behaviour were more likely to choose ABA-based services. Yet for predictors of intensive behavioural intervention selection, only increased severity of restricted/ritualized behaviour and impairments in communication were significant predictors of intervention use. Taken together, these findings suggest autism treatment selection may be driven in part by

autism severity. However, as discussed earlier in this chapter, it is also important to consider other characteristics associated with the autism profile, such as adaptive ability and severity of maladaptive behaviour. Several studies have suggested that higher levels of parental stress are associated with the severity of their child's maladaptive behaviours (Davis & Carter, 2008; Tomanik et al., 2004). In order to address this significant gap in the research, the present study included the use of standardized screening measures to assess the severity of autism symptoms, as well as other important child characteristics, such as the level of adaptive functioning, and severity of maladaptive behaviour.

Parent Factors

Parent factors have been the subject of much research as parents are the primary decision makers and the gatekeeper between the child and the intervention. Parent factors such as education and age have not been found to be associated with the selection of evidence-based treatment (Al Anbar et al., 2010; Miller et al., 2012). On the other hand, parent knowledge about the cause of autism (Al Anbar et al., 2010; Dardennes et al., 2011; Shyu et al., 2010) and attitudes about autism and autism interventions (Carlon et al., 2013) have been linked to treatment selection. In one study, authors examined parent attitudes about autism on several dimensions and found that greater perceived severity of autism lead to the use of "educative" treatments (defined here as behavior or social skills therapy, TEACCH, or PECS) (Al Anbar et al., 2010). In a review by Carlon and colleagues (2013), it was found that parents often consider a multitude of factors - information from trusted sources (e.g., from professionals, research evidence, from the internet) and their own attitudes about the intervention (e.g., perceived efficacy of the intervention and perceived improvement in child) when choosing a treatment for their child. Although parents emphasize the importance of obtaining information, the continued

popularity of treatments lacking scientific evidence suggests that there is a gap between perceived knowledge and actual evidence-based information. Therefore, when examining parent knowledge, it is important to differentiate between perceived knowledge and actual knowledge.

Within Taiwan, little is known about parent perceptions and knowledge of autism and much of the limited literature available has been qualitative in nature and with very small sample sizes ($n \leq 39$). Similar to parent perceptions reported in Western samples (Goin-Kochel & Myers, 2005; Mercer et al., 2006; Selkirk et al., 2009), common perceived causes of autism include genetics and complications during pregnancy/delivery (Chen et al., 2015; Shyu et al., 2010). In addition to these biological causes, some parents also reported supernatural or religious reasons, such as soul possession or punishment from a previous life, as reasons why their child has autism (Shyu et al., 2010). Due to these reasons, these parents often also sought ‘treatment’ from fortune tellers in order to address their child’s symptoms. For instance, one parent chose to change their child’s name, as this was believed to change their child’s ‘fate’ (Shyu et al., 2010). In another qualitative study, Taiwanese mothers reported either blaming themselves for their child’s autism and/or accepted the blame from other family members (Hsu et al., 2017). These few studies suggest that parents often have inadequate knowledge about the etiology of autism (Chen et al., 2015; Hsu et al., 2017; Shyu et al., 2010), which could potentially affect treatment selection. Taken together, these results suggest that identifying parents’ perceived and actual knowledge and attitudes about autism and ABA is important to better understand treatment selection in the Taiwan cultural context.

Intervention Factors

In addition to child and parent factors, intervention accessibility factors such as cost, distance, and availability have also been explored. Barriers to ABA-based service access may

include systemic factors (e.g., education and social services systems that are incompatible or opposed, lack of capacity) or treatment factors (e.g., financial cost, time it takes to implement ABA) (Tzanakaki et al., 2012). Many of these factors are unique to the particular healthcare system of the country/state/province and the majority of studies have examined these factors in Western countries, but the systemic barriers Taiwan parents face have not been described to date. Therefore, a preliminary step is to explore the types autism treatments parents are currently using (i.e., medical and/or biological treatments, school services and community services) in order to understand the factors parents consider when they choose to start or stop a treatment. It is only through understanding the general decision-making patterns for parents in Taiwan, that one can better understand the specific factors that contribute to the selection of ABA-based services in particular. In order to address these gaps in the literature for Taiwanese parents, phase 1 of the present study explored the practice of autism treatments by identifying the types of treatments parents are currently using and have used, as well as barriers and facilitators to accessing these services.

Additional Challenges

In addition to factors affecting parent selection of ABA-based services, a discussion paper by Kelly and colleagues (2019) highlights additional challenges contributing to the implementation gap internationally, such as the dearth of appropriate training courses, use of ABA jargon (Critchfield et al., 2017; Critchfield & Doepke, 2018), differences in cultural and societal contexts, and the commercialized model of ABA-based interventions in some locations (e.g., Australia, Ireland, Middle East) (Keenan et al., 2010). Given this, it is therefore important to assess how ABA-based intervention is viewed in a Chinese society (Chang, 2017). It appears that there are some differences in how ABA programs are delivered in the UK and in China

(Liao et al., 2018). In the UK, parents viewed ABA as mainly a professionally delivered intervention whereas in China, ABA was considered to be the parents' responsibility to implement. Parents in China were also more inclined to value quantity over quality of interventions and 'newer' interventions were also seen as being better. As such, many parents would enroll their children in a mix of different interventions (e.g., ABA, TEACCH, Sensory integration, and music therapy) as they believe more interventions will lead to greater efficacy (McCabe, 2012). However, eclectic approaches have been shown to be less effective than ABA alone (Eikeseth et al., 2002; Howard et al., 2005; ONTABA, 2017).

The literature surrounding the perception of ABA by service users as well as the acceptability of ABA in a Chinese cultural setting is limited. It appears that Taiwan faces similar challenges, however, it is unclear how and to what degree these factors impact the implementation of ABA-based intervention. Thus, an important step is to use a qualitative approach to examine the perceptions of ABA from the perspective of both parents and other relevant stakeholders working in Taiwan (e.g., ABA therapists, special education teachers). This would help develop a better understanding of what (if any) adaptations or education are needed for ABA intervention to be better understood and more accepted within Taiwan society.

Project Overview

Although ABA-based intervention is an evidence-based intervention for autism, there exists a gap in the implementation and usage of these services in Taiwan. Through a mixed methods research design, this project explored factors that contribute to the selection or avoidance of ABA-based intervention, through the use of a quantitative survey, followed by semi-structured interviews with key stakeholders.

Theoretical Frameworks

In order to address this project's main objective, two frameworks were used. In the quantitative survey, the health belief model (HBM) was used as a way of understanding the decision-making process parents use in selecting autism services for their child. Developed in the 1950s by the U.S. Public Health Service, the HBM was first used to explain why many individuals failed to participate in tuberculosis screening programs aimed to prevent and detect disease (Hochbaum, 1958; Rosentock, 1960). Since then, the HBM framework has been applied to a variety of health-seeking behaviours and used to develop effective strategies to increase adoption of various intervention services (e.g., Henshaw & Freedman-Doan, 2009; Smith et al., 2011). It is suggested that whether or not people engage in health-seeking behaviours is affected by several components of the HBM: *perceived severity*, *perceived benefits*, *perceived barriers*, *self-efficacy*, and *cues to action*. Within this framework, perceived severity refers to how severe parents view autism to be and, in particular, the consequences autism may have for their child's future, their family's future, and/or the parent's own future. The HBM suggests that those who score low on perceived severity (i.e., do not feel that the problem is serious) will tend not to engage in health-seeking behaviours which, in this case, means that parents who perceive autism to severely impact their child's life will be more likely to seek autism intervention. Perceived benefits refer to the beliefs and perceptions parents have about the autism intervention, which may influence whether or not parents will select the intervention. Quite simply, if parents believe the intervention is beneficial, this will influence their decision in choosing that intervention. According to the HBM, even if parents perceive autism to be a serious condition, and perceive interventions such as ABA to be beneficial, perceived barriers may prevent parents from selecting ABA for their child. Barriers to ABA intervention may include factors such as financial

constraints, the service being unavailable in their region, time constraints, or stigma (Tzanakaki et al., 2012). The fourth component of the model refers to how individuals view their own ability to implement a certain behaviour. For parents of children with autism, self-efficacy can be conceptualized as the parent's view of their ability to help their child improve (i.e., being able to use the same ABA principles at home). Finally, the HBM states that cues to action are needed in order to prompt individuals to engage in health-promoting behaviours. For parents selecting autism interventions, these cues could be information from the doctor giving the autism diagnosis, TV programs, online blogs, and/or advertising. Cues could also come from their child's behaviours and needs (e.g., child becomes aggressive toward younger sibling).

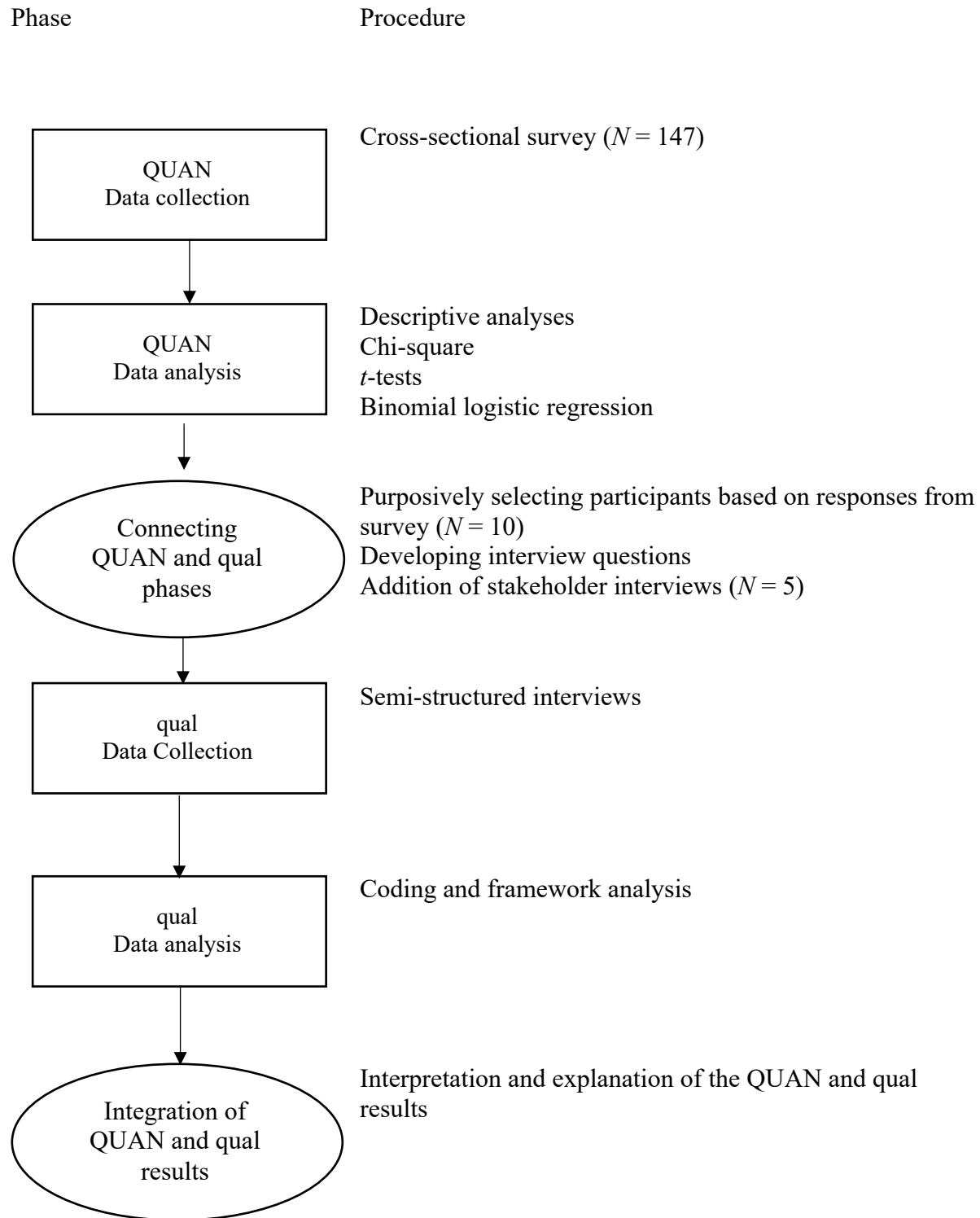
In the qualitative phase of the study, the Diffusion of Innovations theory (Rogers, 2003) was used to explore facilitators and barriers to the use of ABA-based intervention. This theoretical lens was used to explain how and why new ideas, innovations, and/or ideas are adopted by society, by applying it as an explanatory framework in understanding the themes from the semi-structured interviews. The theory focuses on the characteristics of the adopters (i.e., parents), the characteristics of the innovation (i.e., ABA-based intervention), and the environmental context (i.e., Taiwan) (Wejnert, 2002). This framework has been extensively used to examine the research-implementation gap within the healthcare field (e.g., Henderson et al., 2006; Nicol et al., 2011) and has also been applied to autism interventions in the U.S. (Dingfelder & Mandell, 2011; Pickard et al., 2016).

Project Design

Mixed methods research capitalizes on the strengths of both qualitative and quantitative methodologies. Combining different types of data collection and analyses allows a greater breadth and depth of understanding of the phenomenon being studied (Johnson et al., 2007).

Using a mixed methods sequential explanatory design, this project was conducted in two phases, with a quantitative survey followed by qualitative interviews (Creswell et al., 2003; Ivankova et al., 2006). The rationale for this approach is that the quantitative data provides a general understanding of the types of autism treatments and services parents are currently using and what factors contribute to the selection or avoidance of ABA-based interventions. However, this approach alone does not provide enough context about how these barriers contribute to the implementation gap. Therefore, in phase 2, semi-structured interviews were conducted with key informants (i.e., parents and service providers) to clarify and elaborate on the quantitative results obtained in phase 1. In phase 1, a knowledge, attitudes, and practices survey (WHO, 2008) consisting of both close-ended and open-ended questions, was developed using the HBM framework. This survey methodology is extensively used in public health research to gain contextual information about relatively unknown health topics and to explore factors that can be targeted to increase service utilization (WHO, 2008). The subsequent qualitative data collection and analysis allowed for a more in-depth understanding of the results from phase 1 (Creswell et al., 2003; Tashakkori & Teddlie, 1998), by exploring the views of parents and ABA-based service providers. Integration of phase 1 and phase 2 occurred at the methods stage and at the interpretation and reporting stage. At the methods stage, integration occurred in two ways. First, the results of the quantitative survey helped to develop the topic guide used for the semi-structured interviews. Second, parent participants for the interviews were purposively sampled based on their answers from phase 1. At the interpretation and reporting stage, data integration was conducted by first discussing the results of each phase separately in Chapters 2 and 3 and then the data from both phases were combined and integrated in Chapter 4 in order to provide a more complete understanding about the factors that contribute to the implementation gap (Fetters

et al., 2013). Under this model, the quantitative data from phase 1 is given a larger weighting and emphasis (QUAN→qual). Please see Figure 1 for an overview of the project design.

Figure 1*Overview of the Mixed-Methods Research Design*

Chapter 2: Quantitative Phase

Using a survey methodology, the quantitative phase of this project was the first stage of this mixed-methods design. This chapter begins with the specific objectives of the quantitative phase, followed by an explanation about data collection procedures, survey instrument development, and data analysis. The results of the quantitative phase with respect to each research objective are then presented, along with a discussion section.

Specific Research Objectives

Due to the lack of research about the usage of ABA services and other autism interventions in Taiwan, the quantitative phase was largely exploratory in nature with three objectives:

1. To provide a descriptive analysis of the knowledge, attitudes, and practices of parents seeking services for their child with autism in Taiwan.
2. To compare parents who have never used ABA and parents who have used or are currently using ABA for their child, in terms of their knowledge and attitudes regarding autism and ABA. I predicted that parents who have used or are currently using ABA would have greater knowledge about autism and ABA and more positive attitudes about autism and ABA compared to parents who have never used ABA.
3. To identify specific decision-making factors that predict ABA use. Specifically, I hypothesized that greater knowledge of ABA and more positive attitudes towards ABA will predict greater likelihood of ABA use, over and above child characteristics and other parent variables.

Method

Ethical approval was obtained from York University's Human Participants Review Committee. Participants were recruited via ABA professionals in Taiwan and other colleagues

who see children with autism; via community centers; and via parents within the autism community. In order to be included in this study, participants had to be the parent (defined here as the biological parent, step-parent, grandparent, or other type of primary caregiver) of a child (2 to 18 years old) diagnosed with autism or suspected autism by a medical doctor through self-report, and be currently living in Taiwan.

Procedure

Based on the HBM constructs, a knowledge, attitudes, and practice questionnaire was used to examine what parents in Taiwan currently know and what their attitudes and beliefs are about autism and ABA and to describe the interventions they are currently using for their child with autism (see Appendix A for the English version and Appendix B for the Chinese version). The questionnaire was translated from English into Taiwanese Mandarin by a team of undergraduate psychology research students and validated by Professor Hui-Ting Wang, of the National Taiwan Normal University, who is an expert in the field of ABA. The survey was also independently back translated by another undergraduate psychology student to ensure accuracy. The survey was then pilot tested with three parents of children with autism in Taiwan (who did not participate in the final study) and these parents were invited to provide written feedback. From this pilot testing, three questions were edited for clarity and a locally-used autism severity screener that had been included initially was removed in order to shorten the questionnaire length.

Parents were then invited to participate via an online option (using Qualtrics) or a paper-and-pencil option, however 100% of the surveys were completed online. Parents were provided a voucher (equivalent to \$6 CAD) for the completion of this survey, which took approximately 50 minutes to complete.

Participants

The participants ($n = 147$) completing the questionnaires were mainly biological parents ($n = 145$, 99%), women ($n = 132$, 90%), and married ($n = 127$, 86%). The age range was between 31 to 64 years ($M = 41.36$, $SD = 5.77$). The participant was asked to answer questions in reference to themselves as well as their partner (where applicable). Demographic information on the sample, such as religious belief, education level and employment status are presented for parents in Table 1.1.

Table 1.1

Demographic Information of Female and Male Parent Participants

Variable	Female n (%)	Male n (%)
Religion		
Taoism	30 (20)	45 (31)
Buddhism	29 (20)	26 (18)
Christianity	25 (17)	13 (9)
No Religion	57 (39)	50 (35)
Other	6 (4)	10 (7)
Education		
Elementary School	2 (1)	0
Middle School	2 (1)	9 (6)
High School	15 (10)	19 (13)
College/University	92 (63)	78 (54)
Masters and above	36 (24)	38 (26)
Employment Status		

Full-time	61 (41)	129 (90)
Part-time	10 (7)	1 (1)
Unemployed	3 (2)	4 (3)
Full-time parent	69 (47)	10 (7)
Working more than one part-time job at the same time	4 (3)	0

Note: Female participants ($n = 147$) and male participants ($n = 144$)

Measures

Demographic Information

Participants were asked to fill out one survey for their family. Information related to the parents such as age, nationality, education level, employment status, and religious belief were collected. Information related to the child such as age, gender, age of diagnosis, and school status were also collected.

Autism Diagnosis and Severity

In Taiwan, all autism diagnoses are given by medical doctors. The label of “suspected autism” may also be given for children under the age of 6, prior to a confirmed diagnosis of autism at an older age. Given this difference, parents were asked whether their child was given an autism diagnosis or a suspected autism label. In order to ensure that the child was eligible for the study, participants were asked to fill out an autism symptom screener, the Social Communication Questionnaire (SCQ) - Chinese version (Gau et al., 2011). The SCQ is a 40-item, parent report measure with a recommended cut-off score of 15 or greater as indicative of possible autism, however findings from Corsello et al. (2007) suggest that a lower cut-off of 11 could increase the sensitivity of the measure for children younger than 8 years or age. Based on

the existing research and examining the distribution of SCQ scores in the sample, a decision was made to include children if they either had a confirmed diagnosis of autism with an SCQ score of 11 or higher, or a diagnosis of suspected autism with a score of 13 or above on the SCQ. Two participants were removed from analyses as they did not meet the minimum SCQ score.

Daily Functioning

In addition to assessing for autism severity, the daily functioning skills of the child participants were measured in terms of adaptive and maladaptive behaviour. The GO4KIDDS Brief Adaptive Scale (Perry et al., 2015) was used as brief assessment of adaptive behaviour. This adaptive scale consists of 8 items covering four areas (level of support needed, communication, social interaction, and daily living skills) with responses scored on a 5-point Likert-type scale with higher scores indicating greater adaptive skills. The scores were summed to obtain an overall adaptive behaviour score, with the minimum possible score of 8 and a maximum possible score of 40. The internal consistency of this scale in a Canadian sample was excellent (Cronbach's $\alpha = 0.87$) and had very good convergent validity ($r = 0.81$) with the Scales of Independent Behavior (SIB-R Short Form; Bruininks et al., 1996) (Perry et al., 2015). Similarly, in an independent study examining the use of the brief adaptive scale by special education teachers, excellent internal consistency ($\alpha = .93$) and convergent validity ($r = .81$) with the teacher version of the Vineland Adaptive Behavior Scale was reported (Pan et al., 2019). In order to assess the occurrence of maladaptive behaviour, the survey included three questions which were adapted from the Behaviour Problems Inventory for Individuals with Intellectual Disabilities (Rojahn et al., 2012). Responses were scored on a 5-point frequency scale ranging from 0 to 4, with higher scores indicating a higher frequency of maladaptive behaviour. The

three items were summed to create a total maladaptive score, with a minimum possible score of 0 and a maximum possible score of 12.

Perceived and Actual Knowledge about Autism

Parents were first asked to rate their own perceived knowledge of autism compared to the general population (Section III, item 1) on a 5-point scale ranging from “much lower than the general population” to “much higher than the general population”. Actual knowledge was assessed using 10 factual statements about autism with three answer options: “true”, “false”, or “I don’t know”. Correct answers were scored one point, with a maximum score of 10 for autism knowledge. Nine autism statements were originally used in a group of Canadian parents in a previous study by Solish & Perry (2008), who developed a 20-item knowledge scale consisting of 10 autism questions and 10 ABA questions. The reliability for this original 20-item scale was .81 and these questions were rationally derived via consultation with Canadian professionals in the field (i.e., psychologists and ABA therapists). Two additional statements (Section III, item 2B and 2F) were added based on discussion with local professionals in Taiwan and from literature review.

In addition, an open-ended question was asked regarding the cause(s) of autism (Section III, item 2K) and answers were coded into one or more of the following categories: (a) biological cause of autism (e.g., genetics, abnormal brain defects), (b) environmental cause, (c) cause is unknown, and (d) autism myths (i.e., unproven or disproven causes of autism).

Perceived and Actual Knowledge about ABA

Similar to the procedure described previously, parents were asked to rate their own perceived knowledge of ABA compared to that of the general population (Section IV, item 1). Actual knowledge regarding ABA methodology was assessed using nine factual statements

about ABA, with three answer options: “true”, “false”, or “I don’t know”, with scores ranging from 0 to 9. Four ABA statements were adapted from Solish and Perry (2008) and five additional statements (Section IV, items 2B,2C,2E,2H,2I) were added based on discussion with local professionals in Taiwan and literature review.

Attitudes about Autism

In order to examine attitudes towards autism, parents were provided seven statements and asked about the degree to which they agreed on a 5-point Likert-type scale with the following options: (1) Strongly disagree (2) Disagree (3) Neither disagree nor agree (4) Agree, and (5) Strongly agree. In particular, statements assessing the *perceived severity of autism* were the following: “Even though my child has autism, he/she can still achieve many things” and “My child can still have a happy life”. Attitudes about social support were also addressed with the following statements: “My friends are a source of support for me whenever I need help for my child with autism” and “My family members are a source of support for me whenever I need help for my child with autism”. Parents were provided four statements on the same 5-point Likert-type scale about treatment-seeking attitudes towards autism services, and in particular, the participants’ *self-efficacy* about their ability to help their child was assessed with the following statement: “I am very confident about deciding which service and treatment to use for my child”. In an open-ended question, parents were also asked about how people in the community generally treated individuals with autism, and responses were coded as “negative”, “positive”, or “neutral”.

Attitudes about ABA

Parents were given 13 statements regarding their attitudes about ABA, to rate on a 5-point Likert-type scale with the same response options listed above. Eleven of these questions

(Section IV: items 3A, 3B, 3D, 3E, 3F, and 3H-3M) were adapted from Solish and Perry (2008). In particular, the *perceived benefits* of ABA were assessed. For instance, parents were given the following statement to rate: “I believe that ABA is likely to result in permanent improvement for children with autism”.

Practice of Autism Treatments

Parents were asked about their usage, satisfaction, *cues to action*, and reasons for stopping various medical and/or biological treatments, school services and community services. To assess the use of medical and biological treatment, participants were provided a list of six treatments and were provided three response options: (a) Never used (b) Used before but stopped and (c) Currently using. Parents were also given the opportunity to add their own medical/biological treatment if it was not provided in the list. Parents were then asked to rate their overall level of satisfaction with the current medical/biological treatments their child was receiving on a 5-point Likert-type scale with the following response options: (a) Very dissatisfied (b) Dissatisfied (c) Neutral (Neither satisfied nor dissatisfied) (d) Satisfied and (e) Very satisfied. Parents were also asked about their reasons for stopping medical/biological treatment and asked to check off all responses that apply and/or provide their own reason: (a) Service was too expensive (b) Service was stopped by the medical professional (c) Service was too far (e) Did not see improvement in child (f) Wanted to try something else and (g) Other (Please specify:).

Parents were asked about their cues to action for medical and biological treatment with the following question, “When choosing a medical treatment for your child, what factors do you consider?”. The following responses were provided and parents were asked to check all that apply and/or provide their own reason if it was not listed: (a) Cost (b) Distance from home/work (c) Scientific evidence (d) Recommendation from medical professionals (e) Recommendation

from school/other service professionals (f) Recommendation from family (g) Recommendation from friends (h) Recommendation from religious leaders (i) Recommendation from celebrities (j) TV program sources (k) Internet sources (l) Book sources and (m) Other (Please specify:).

For within-school autism services, parents were asked, “What services are currently being used by your child in school? (check all that apply)” and given the following options as well as the option to add a service that was not listed: (a) no services are offered at my child’s school (b) occupational therapy (c) physical therapy (d) speech therapy (e) Other (please specify:). Parents were asked about their overall satisfaction with in-school services on a 5-point Likert-type scale ranging from “Very dissatisfied” to “Very satisfied”.

For community services, parents were provided a list of 13 commonly used local community services and were also given the option to provide their own responses if the service was not listed. For each of the services listed, parents were given the following response options: (a) available in my city/town and we currently use, (b) Available in my city/town and we have used in the past but have now stopped, and (c) Not available in my city/town but we need. Parents were asked to rate their overall satisfaction with the out-of-school services they were using on a 5-point Likert-type scale. Parents were also asked about their reasons for stopping community services as well as their cues to action, in the same manner as described previously for medical and biological treatments.

Out of all the medical/biological treatments, schools services and community services used, parents were asked to select the intervention they believed lead to the most improvement in their child, and were asked to rate their child’s overall functioning prior to and after this intervention as well as perceived improvement in various skills (i.e., social and play, academic,

communication, and self-help) and reduction in problem behaviours as a result of this intervention.

Practice of ABA-based Treatments

Parents were asked about their usage of ABA-based services and were provided a brief definition of what these interventions encompass: “There are many different types of ABA such as Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI) and Pivotal Response Training (PRT). Please answer the following based on your experiences with ABA services.” Parents were then asked to select one of the following three statements that best described their situation: (a) “My child is currently receiving ABA services”, (b) “My child used to receive ABA services but has stopped”, and (c) “My child has never received ABA services”. ABA-based service use was dichotomized into ABA-users (i.e., selection of response *a* or *b*) and non-users (i.e., selection of response *c*). ABA-users were further asked about treatment intensity (i.e., number of hours a week of ABA their child is receiving/use to receive) and duration (i.e., number of months of ABA their child has received). They were also asked to rate their child’s overall functioning prior to ABA and after ABA, as well as perceived improvement in various skills (i.e., social and play, academic, communication, and self-help) and reduction in problem behaviours. Parents were asked about their overall satisfaction with ABA-based services on a 5-point Likert-type scale. If parents had stopped using or had never used ABA-based services, they were asked about their reason(s) and were provided a list of four options as well as the option to provide their own reason if it was not listed.

Analyses

Prior to analyses, the survey data were first examined for completeness (i.e., 70% or more of the survey completed), child diagnosis (as detailed above), and screened for outliers. In total,

there were 283 clicks of the survey link, however only 149 participants completed 70% of the survey or more and met the cut-offs for diagnoses. An additional 2 participants were dropped as outliers.

Preliminary analyses were conducted to examine the reliability of the knowledge scales and the ABA attitudes scales. Descriptive analyses were conducted for demographic measures as well as for the knowledge, attitude, and practice variables. Subgroup comparisons, such as between ABA service users and non-ABA service users, were conducted using chi-squares or *t*-tests.

Results

Preliminary Analyses

Initial reliability analyses were conducted on the hypothesized predictors (i.e., Autism knowledge, ABA knowledge, and ABA attitude measures) in order to determine whether particular items should be dropped or retained to comprise of a total score to be used for further analyses.

For autism knowledge questions, the 10 items had a coefficient alpha of .59, which is rather low. However because the questions were adapted from a questionnaire with a high Cronbach's alpha (Solish & Perry, 2008) and used as an exploratory measure in this population, the lower reliability coefficient was considered acceptable for this stage of research. No items were highly discordant from the rest and therefore, the total score was considered to be acceptable as a measure of autism knowledge. For the ABA knowledge questions, there were no highly discordant items and the nine 9 items had a coefficient alpha of .74. Therefore, all the items were retained for the ABA knowledge scale. For ABA attitudes, the coefficient alpha was .89 and all items were retained.

Child Characteristics

The majority (82%) of the children were male and their ages ranged from 2 to 18 years. Most of the children had a confirmed diagnosis of autism (78%), and SCQ scores ranged from 11 to 38. Adaptive scores ranged from 12 to 39 and maladaptive scores ranged from 3 to 12. The majority (94%) of children were currently in school, and most (55%) were in mixed classes (i.e., regular class with special education supports, special education classes within a mainstream school). Additional information is presented in Table 1.2.

Table 1.2

Descriptive Information for Child Participants

Variable	<i>n (%) or M (SD)</i>
Age at time of survey completion	7.99 (4.28)
Gender	
Male	121 (82)
Female	26 (18)
Autism Diagnosis and Severity	
Confirmed Diagnosis	115 (78)
Suspected Diagnosis	32 (22)
SCQ scores	21.33 (6.38)
Daily functioning	
Adaptive Scores	27.09 (6.43)
Maladaptive Scores	6.61 (2.34)
School	
Mainstream class only	23 (16)

Mixed Mainstream classes	80 (54)
Special education class	25 (17)
Special education school	9 (6)
Not attending school	9 (6)
Status unknown (missing data)	1 (.7)

Note. Child participants ($n = 147$)

Objective 1: Description of Knowledge, Attitudes, and Practices

Knowledge

Of all parents in the sample ($n = 147$), 61% ($n = 89$) perceived that they had higher than average knowledge of autism when compared to the general public. Of the 10 factual questions, parents had the most difficulty with the statement ‘Most children with autism also have special abilities’, with two-thirds of parents answering incorrectly. Please see Table 1.3 for a breakdown of parent answers. When asked about the cause of autism, the majority of parents (83%, $n = 122$) cited a biological cause of autism, followed by an environmental cause (21%, $n = 31$), and an unknown cause (18%, $n = 26$). A subset of parents (12%, $n = 18$) endorsed autism myths, and reported mother’s stress, lack of companionship, and parenting styles as causes of autism.

Table 1.3

Summary of Parent Responses on Knowledge of Autism

Statement	Correct Answer	n (%) Correct
A. The earliest signs of autism include poor response to being called by name and lack of pointing.	T	120 (82)
B. Most children with autism also have special abilities (e.g. good memory, good at math).	F	51 (35)
C. Children with autism are good at understanding the thoughts, feelings, and intentions of other people.	F	134 (91)
D. Children with autism do not always, but may, have intellectual disability.	T	128 (87)

E. Autism affects children of all racial, ethnic and social class backgrounds with equal frequency.	T	105 (71)
F. Autism can be cured.	F	118 (80)
G. Children with autism range from being nonverbal to being verbal.	T	142 (97)
H. Children with autism are known to have a wide variety of interests and good social skills.	F	137 (93)
I. Children with autism may communicate using sign language or pictures.	T	140 (95)
J. Children with autism usually engage in play that looks like that of other children their age.	F	122 (83)

In terms of perceived ABA knowledge, 45% ($n = 66$) reported that they did not perceive their knowledge to be any higher than that of the general population. Parents had difficulty with answering several of the ABA items and did not appear to understand ABA methodology. For instance, the majority of parents answered incorrectly that at the beginning of ABA treatment, most children react to praise and tangible rewards with the same reaction. In addition, a large portion of parents also responded incorrectly that teaching materials should not be varied as this may confuse the child. Please see Table 1.4 for a summary of parent responses.

Table 1.4

Summary of Parent Responses for Knowledge of ABA

	Correct Answer	<i>n (%)</i>
		Correct
A. After a child has mastered a task with prompting, prompts should be faded so that the child can eventually demonstrate the skill independently.	T	126 (86)
B. There is no scientific evidence showing the benefits of ABA.	F	85 (58)
C. ABA is only used with the child during sessions and parents should not try to continue the therapy at home.	F	118 (80)
D. In ABA it is often best to teach the child a complex task by breaking it down into parts rather than teaching the task as a whole.	T	120 (82)

E. ABA is best used with other types of therapies (such as acupuncture, SSRI).	F	45 (31)
F. In ABA, you should not vary the teaching materials or the wording of the instruction because this will just confuse the child.	F	37 (25)
G. At the start of therapy most children respond just as well to praise (e.g., someone saying “good job!”) as to tangible reinforcers or rewards (e.g., candy).	F	32 (22)
H. 4 hours a week of ABA therapy is the same effectiveness as 20 hours a week of ABA therapy.	F	99 (67)
I. ABA is beneficial for working on social and behavioral difficulties.	T	103 (70)

Attitudes

Table 1.5 shows parent responses to each question. In terms of perceived severity of autism, many parents were positive about their child’s future. Although many felt that their child’s autism was not their fault, the majority felt stress due to their child’s autism diagnosis, and only half of parents endorsed family members and friends as a source of support. In the open-ended question, the majority (76%, $n = 110$) of the respondents reported that society held a negative view of autism.

Table 1.5

Summary of Parents Responses for Attitudes about Autism

Statement	<i>n (%)</i> Agree
A. Even though my child has Autism, he/she can still achieve many things	126 (86)
B. My child can still have a happy life	127 (86)
C. I feel like my child’s autism is my fault	17 (12)
D. It is the government’s responsibility to provide appropriate services for autism	128 (87)
E. I feel a lot of stress due to my child’s autism	123 (84)
F. My family members are a source of support for me whenever I need help for my child with autism	81 (55)
G. When we go to a public place, people treat my child negatively (i.e. ignore, scold, make fun of)	49 (33)
H. My friends are a source of support for me whenever I need help for my child with autism	74 (50)

I. I believe that the higher the number of medical treatments my child uses, the better my child's outcome will be	88 (60)
J. I believe that the higher the number of therapy services my child uses, the better my child's outcome will be	116 (79)
K. I am very confident about deciding which service and treatment to use for my child	83 (57)

In terms of attitudes towards ABA, many parents held positive beliefs about the efficacy of ABA and believe that ABA will help in addressing various areas of concern (i.e., social and play skills, communication, self-help, problem behaviour). Half of the parents responded that they were comfortable with the procedures and techniques used in ABA, and that ABA would likely result in permanent improvement for their child. Please see Table 1.6 for summary of the responses.

Table 1.6

Summary of Parent Responses for Attitudes about ABA

Statement	<i>n (%)</i> Agree
A. I believe that ABA is a major breakthrough in the treatment of autism.	77 (52)
B. I am convinced that ABA I will turn out to be another false miracle like other "miracle cures" for autism.	15 (10)
C. I believe that medical treatments are more effective than ABA therapy.	15 (10)
D. I believe that ABA is likely to result in permanent improvement for children with autism.	83 (57)
E. I feel comfortable with the procedures and techniques used in ABA therapy.	73 (50)
F. I am skeptical about 'success stories' that I hear about the use of ABA for children with autism.	18 (12)
G. I believe that ABA helps children with autism to improve more than any other form of intervention.	68 (46)
H. No matter what, I will always continue to use behavioural principles with my child with autism.	66 (45)
I. I believe that ABA will help my child to develop better social and play skills.	86 (59)
J. I believe that ABA will help my child to develop better academic skills.	72 (49)
K. I believe that ABA will help my child to develop better communication skills.	83 (57)

L. I believe that ABA will help my child to develop better self-help skills.	96 (65)
M. I believe that ABA will help to eliminate or reduce my child's problem behaviour (e.g., tantruming, self-injury, and/or aggression).	92 (63)

Practices

Parents were asked about the different types of medical and other biological treatments used for their child for their autism symptoms, as well as the services their child received both in school and in the community. Only 36% ($n = 53$) reported that they were currently using at least one or more medical and/or other biological treatments, and the top three treatments used were vitamin supplements (62%, $n = 33$), Ritalin/Concerta (38%, $n = 20$), and special diets (15%, $n = 8$). Similarly, only 35% ($n = 51$) reported having stopped at least one or more medical and/or biological treatment. The most common treatments that were stopped were vitamin supplements ($n = 28$, 55%), acupuncture ($n = 19$, 37%), and Ritalin/Concerta ($n = 10$, 20%). In terms of the reasons for stopping these treatments, the main reasons parents reported was that the medical professional stopped the treatment. Please see Table 1.7 for a summary.

Table 1.7

Reasons for Stopping Medical and/or Biological Treatments

Reason	n (%)
Medical/Healthcare Professional stopped services	21 (41)
Did not see improvement in the child	14 (28)
Wanted to try other services	14 (28)
Cost	11 (22)
Distance	9 (18)
Uncertainty of effects	2 (4)
Other	8 (16)

Note. Parents who have stopped at least one medical treatment ($n = 51$)

Of the children currently attending school ($n = 137$), many of the children used occupational therapy services (52%, $n = 71$), speech therapy (41%, $n = 56$), and physiotherapy (29%, $n = 40$), however, some parents (21%, $n = 29$) reported that their school did not offer any services for their child. The majority (78%, $n = 115$) of parents reported currently using at least one community service. Similar to school services used, occupational therapy, speech therapy, and physiotherapy were the top services currently used by children in the community. Please see Table 1.8 for a breakdown of services currently used in the community.

Table 1.8

Summary of Currently Used Community Services

Services	<i>n</i> (%)
Occupational therapy	92 (80)
Speech Therapy	77 (67)
Physiotherapy	60 (52)
Sensory Integration	46 (40)
Parent Training	35 (30)
Parent Support	33 (29)
Music Therapy	21 (18)
Respite Care	16 (14)
Art Therapy	16 (14)
Relationship Development Intervention	14 (12)
Pet Therapy	8 (7)
Psychotherapy	7 (6)
Social Skills Therapy	4 (4)
Facilitated Communication	1 (1)

Note. Parents currently using community services ($n = 115$)

In addition, more than half of parents ($n = 99$, 67%) reported at least one community service they have stopped using. In terms of previously used services, the most common interventions were sensory integration ($n = 48$, 49%), physiotherapy ($n = 42$, 42%), parent training ($n = 42$, 42%), and occupational therapy ($n = 40$, 40%). The termination of services was

typically due to the professional's decision, the cost of the services, and/or to a lack of perceived improvement in the child (see Table 1.9 for additional factors).

Table 1.9

Reasons for Stopping Community Services

Reason	<i>n</i> (%)
Medical/Healthcare Professional stopped services	40 (40)
Cost	36 (36)
Did not see improvement in the child	30 (30)
Wanted to try other services	23 (23)
Distance	19 (19)
Scheduling difficulties	8 (8)
Child improved enough	3 (3)
Lack of Professionalism	1 (1)

Note. Parents who have stopped using atleast one community service ($n = 99$)

In terms of ABA-based service use, only 12 parents (8% of the sample) reported currently using ABA and some (20%, $n = 30$) reported having previously used ABA services but having stopped. The majority (71%, $n = 105$) of the sample reported never having used ABA. For parents who had never used ABA, the high cost and distance were common barriers reported, but also 30% ($n = 28$) reported a lack of awareness about the existence of ABA, (see Table 1.10 for summary of barriers to ABA-based services). For parents who had used but stopped ABA services, reasons for stopping include cost (37%, $n = 11$), wanting to try different things (33%, $n = 10$), and not seeing improvements in their child (23%, $n = 7$).

Table 1.10

Summary of Barriers to ABA-based Services

Barriers	<i>n</i> (%)
Cost	39 (41)
Did not know about existence of service	28 (30)
Distance	26 (28)
Wanted to try different things	9 (10)
Could not find ABA-based services	6 (6)
Was not told by professionals	6 (6)

No time	2 (2)
Lack of improvement seen in child	2 (2)

Note. Parents who have never used ABA-based services ($n = 94$, 11 missing responses)

Of those parents who were ABA users (either previously or currently, $n = 42$), the majority (69%, $n = 29$) of children received ABA treatment for 4 hours or less per week. In terms of duration of treatment, almost half (48%, $n = 20$) of the children received 6 months or less of ABA treatment. Only one parent reported their child receiving 20 hours or more of ABA treatment per week and with a duration of 2 or more years, which would be considered the optimal dose in North America.

The majority (88%, $n = 37$) of parents reported seeing at least some improvements in their child that they attributed to the ABA treatment. In particular, parents saw the most improvement in their child's social and play skills, with half of the parents (52%, $n = 22$) reporting some progress. In comparison, parents reported the least progress in academic skills, with 24% ($n = 10$) reporting no improvement at all. Overall, over half of the parents (57%, $n = 24$) reported that they were satisfied with their child's ABA services. Parents of children currently receiving ABA services were more likely to report that they were satisfied when compared to previous ABA users, $\chi^2 (1, N = 42) = 4.71, p = .030, V = .34$. Of all the autism services, parents reported that occupational therapy, parent training, and ABA-based intervention led to the biggest improvement in their child. Very few parents attributed improvements in their child to medical treatments. Please see Table 1.11 for summary of parent responses.

Table 1.11

Parent Report of Most Efficacious Services

Service	n (%)
Occupational therapy	62 (43)
ABA-based services	22 (15)
Parent training	21 (15)

General Psychotherapy	11 (8)
Music therapy	5 (4)
Medical treatment	4 (3)
Speech therapy	4 (3)
Physiotherapy	2 (1)
Facilitated communication	3 (2)
Art therapy	3 (2)
Pet therapy	1 (1)
Sensory integration	1 (1)
Mix of different interventions	1 (1)
Other	4 (2)

Note. $n = 144$, 3 missing responses

When asked about the different factors that parents ($n = 146$, one missing response) consider for selecting medical and other biological treatments, the most common factors were distance (74%, $n = 108$), recommendations from medical professionals (62%, $n = 90$), recommendations from schools/other service providers (57%, $n = 83$), and cost (57%, $n = 83$). Similarly, factors parents ($n = 144$, three missing responses) considered when selecting non-medical interventions were distance (83%, $n = 119$), cost (69%, $n = 100$), and recommendations from medical professionals (69%, $n = 99$) and from school/other professionals (56%, $n = 80$).

Objective 2: Comparison of Knowledge and Attitudes between ABA Users and Non-users

Scores of ABA users (current and past users, $n = 42$) and non-users ($n = 105$) were compared using independent-samples t -tests. In terms of knowledge of autism, ABA users on average had higher scores ($M = 8.67$, $SD = 1.18$) than non-users ($M = 7.93$, $SD = 1.71$). This difference was significant $t(145) = 2.54$, $p = .012$, $d = .46$. For knowledge of ABA, as hypothesized, ABA users ($M = 6.43$, $SD = 1.42$) had significantly higher scores than non-users ($M = 4.71$, $SD = 2.28$); $t(119.50) = 5.49$, $p < .001$, $d = .83$.

A chi-square test was used to examine differences in perceptions of autism cause between ABA users and non-users, and no significant associations were found for any of the causes: Biological ($\chi^2(1, N = 147) = 2.33$, $p = .127$, $V = .13$), Environmental ($\chi^2(1, N = 147) = .69$, p

= .406, $V = .07$), Unknown ($X^2(1, N = 147) = .04, p = .838, V = .02$, and Myths ($X^2(1, N = 147) = 1.42, p = .233, V = .10$).

Chi-squares were used to examine the relationship between ABA users and non-users and their attitudes towards autism and ABA. No significant associations were found for any of the attitude statements for autism (see Table 1.12).

Table 1.12

Comparison between ABA Users (Current or Past) and Non-Users on Attitudes about Autism

Statement	ABA users (% agree)	Non-users (% agree)	X^2
A. Even though my child has Autism, he/she can still achieve many things	81	88	1.09
B. My child can still have a happy life	86	87	.02
C. I feel like my child's autism is my fault	14	11	.43
D. It is the government's responsibility to provide appropriate services for autism	91	86	.60
E. I feel a lot of stress due to my child's autism	88	82	.84
F. My family members are a source of support for me whenever I need help for my child with autism	57	54	.10
G. When we go to a public place, people treat my child negatively (i.e. ignore, scold, make fun of)	31	34	.15
H. My friends are a source of support for me whenever I need help for my child with autism	48	51	.17
I. I believe that the higher the number of medical treatments my child uses, the better my child's outcome will be	60	60	.00
J. I believe that the higher the number of therapy services my child uses, the better my child's outcome will be	79	79	.00
K. I am very confident about deciding which service and treatment to use for my child	67	52	2.49

Note. ABA users ($n = 42$) and non-users ($n = 105$)

For statements about ABA attitudes, ABA group status was related to six statements (see Table 1.13). ABA users were more likely to endorse feeling comfortable with procedures and techniques used in ABA ($X^2(1, N = 147) = 8.84, p = .003, V = .25$) and to believe that ABA will bring more improvement for children with autism than any other intervention ($X^2(1, N = 147) =$

5.80, $p = .016$, $V = .20$). Furthermore, ABA users were more likely to report that they would continue to use behavioural principles for their child with autism ($\chi^2(1, N = 147) = 8.93$, $p = .003$, $V = .25$). ABA users were also more likely to report believing that ABA will help in reducing behavioural problems ($\chi^2(1, N = 147) = 4.65$, $p = .031$, $V = .18$). In contrast, non-users were more likely to report that they were skeptical about the “success stories” they have heard about using ABA for children with autism ($\chi^2(1, N = 147) = 4.73$, $p = .030$, $V = .18$). Non-users were more likely to believe that medical treatments are more effective than ABA therapy ($\chi^2(1, N = 147) = 4.85$, $p = .028$, $V = .18$).

Table 1.13

Comparison between ABA Users (Current or Past) and Non-Users on Attitudes towards ABA

Statement	ABA users (% agree)	Non-users (% agree)	χ^2
A. I believe that ABA is a major breakthrough in the treatment of autism.	62	49	2.14
B. I am convinced that ABA I will turn out to be another false miracle like other “miracle cures” for autism.	43	50	.54
C. I believe that medical treatments are more effective than ABA therapy.	52	71	4.85*
D. I believe that ABA is likely to result in permanent improvement for children with autism.	69	51	3.79
E. I feel comfortable with the procedures and techniques used in ABA therapy.	69	42	8.84**
F. I am skeptical about ‘success stories’ that I hear about the use of ABA for children with autism.	45	65	4.73*
G. I believe that ABA helps children with autism to improve more than any other form of intervention.	62	40	5.79*
H. No matter what, I will always continue to use behavioural principles with my child with autism.	64	37	8.93**
I. I believe that ABA will help my child to develop better social and play skills.	64	56	.81

J. I believe that ABA will help my child to develop better academic skills.	57	46	1.57
K. I believe that ABA will help my child to develop better communication skills.	76	61	3.08
L. I believe that ABA will help my child to develop better self-help skills.	69	51	3.79
M. I believe that ABA will help to eliminate or reduce my child's problem behaviour (e.g., tantruming, self-injury, and/or aggression).	76	57	4.65*

Note. ABA users ($n = 42$) and non-users ($n = 105$), * $p < 0.05$, ** $p < .01$, $df=1$

Objective 3: Predictors of ABA-Based Service Use

Binomial logistic regression was used to examine the relative strength of predictors of ABA-based service use (i.e., never used vs. current or past use of ABA). Since a binomial logistic regression depends on maximum likelihood estimation, a conservative number of independent predictors was chosen relative to the sample size of 147. The following seven variables were chosen as independent predictor variables including Child Variables (status of diagnosis (i.e., confirmed or suspected autism), brief adaptive score, maladaptive score, SCQ score) and Parent Variables (autism knowledge, ABA knowledge, and ABA attitudes).

Prior to analyses, all predictors were examined to ensure that statistical assumptions were not violated. Box and whisker plots were examined for extreme outliers. Multicollinearity was assessed via tolerance and Variance Inflation Factor (VIF) values. Tolerance values of less than 0.1 and/or VIF values greater than 10 are considered indicative of multicollinearity violations (Menard, 1995; Myers 1990). Predictors were all well within the acceptable cut-off points. The assumption of linearity of independent continuous variables and log odds was assessed via the Box-Tidwell (1962) procedure. A Bonferroni correction was applied using all 13 terms in the model resulting in statistical significance being accepted when $p < .00385$ (Tabachnick & Fidell, 2019). Based on this assessment, all continuous independent predictors met the statistical assumption of linearity.

The variables were entered hierarchically in three blocks. In block 1, child characteristics were entered. Specifically, a diagnosis of either autism or suspected autism (suspected autism as reference group), SCQ scores (severity of autism), maladaptive behaviour scores, and Brief Adaptive Scale scores were included. These child characteristics were selected and entered first in order to control for child characteristics which may influence decision-making. After controlling for the other predictors, only the child's SCQ score significantly contributed to the model ($p = .037$), however, the overall model at block 1 was not significant ($p > .05$).

In block 2, parent knowledge of autism was entered. Due to a heavy skew towards higher scores, the autism knowledge variable was dichotomized into low (i.e., score of 7 or lower) and high (i.e., score of 8 or higher), with low scores being the reference group. When autism knowledge was added into the equation it significantly contributed to the model ($p = .040$) and SCQ scores were no longer a significant predictor of ABA service use. The overall model in block 2 was significant, $p = .024$.

In block 3, parent knowledge of ABA and attitudes towards ABA were entered. After controlling for the other predictors, ABA knowledge emerged as the sole predictor of ABA service use ($p = .002$). The logistic regression model was statistically significant, $\chi^2 (7) = 15.284$, $p < 0.001$. The model significantly explained 24% (Nagelkerke R square) of the variance in ABA service use. Please see Table 1.14 for a summary of the final model.

Table 1.14

Logistic Regression Predicting Likelihood of ABA Service Use Based on Child and Parent Factors

	<i>B</i>	SE	Wald	<i>df</i>	<i>p</i>	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
Brief Adaptive Score	-.010	.034	.093	1	.761	.990	.926	1.058
Maladaptive Score	.009	.092	.010	1	.922	1.009	.843	1.208
SCQ Score	.052	.033	2.459	1	.117	1.053	.987	1.124
Diagnosis ¹	.226	.558	.163	1	.686	1.253	.420	3.741
Autism Knowledge ²	.715	.627	1.299	1	.254	2.044	.598	6.987
ABA Knowledge*	.431	.141	9.366	1	.002	1.539	1.168	2.028
ABA Attitudes	.011	.048	.051	1	.822	1.011	.920	1.111
Constant	-5.415	2.094	6.690	1	.010	.004		

Note: ¹ Dichotomous: confirmed diagnosis vs. suspected diagnosis

² Dichotomous: ASD knowledge high low

* $p < 0.05$

Discussion

The first phase of this study explored the current service utilization patterns of 147 parents of children with autism in Taiwan. Parents completed an online survey examining their knowledge, attitudes, and practices of autism and ABA-based intervention. This study was largely exploratory in nature and findings from the three research objectives are discussed below.

Objective 1: Descriptive Analyses

The majority of parents in this sample had high knowledge about autism and viewed autism as (1) biological and/or (2) environmental in origin. These results match survey findings from various other studies conducted outside of Taiwan (Chaidez et al., 2018; Dardennes et al., 2011), and are consistent with the current scientific understanding of autism etiology (Bölte et al., 2019). Although the current study's sample characteristics (i.e., high education) are similar to the samples found in previous studies conducted in Taiwan, the current study's findings are inconsistent with earlier reports suggesting that parents tend to believe autism is caused by non-biological (Chen et al., 2015) or supernatural reasons (Shyu et al., 2010). However, these previous studies were limited in their sample size (i.e., 39 and 13 respectively) and were both qualitative in nature. The difference between the current study's findings and those of earlier studies could also reflect the improvement in the knowledge of autism amongst parents in Taiwan in recent years.

Parents in this present sample reported feeling optimistic about their child's future. At the same time, however, most parents also reported feeling stressed due to their child's diagnosis. Parents reported various factors that may contribute to this stress, such as the lack of perceived support from friends and family, as well as the negative attitudes held by society. These reported stressors are consistent with previous research with Taiwanese mothers, which found that a perceived lack of support was linked to higher levels of caregiver strain (Lin, 2014). In the current study, parents reported that society held many misconceptions about autism, and this finding has also been highlighted by previous research in Taiwan (Hsu et al., 2017) and with an ethnically Chinese sample in Mainland China (Wang et al., 2012). These findings suggest that, while parents themselves may have a positive outlook regarding the diagnosis, the lack of social

support and understanding from extended family members and public members of society may contribute to feelings of stigma.

In comparison to the high knowledge about autism, knowledge about ABA was low, which may not be surprising given the paucity of ABA-based services in Taiwan. Parents had difficulty with many of the methodology questions regarding ABA and a lack of knowledge about ABA was a major barrier reported by non-users. Despite poor knowledge about ABA however, approximately half of the parents still reported high perceived benefits of ABA-based intervention for improvement of skills in the various domains (i.e. social and play, academic, communication, and self-help) regardless of whether they had ever used ABA-based intervention. This suggests that the lack of usage of ABA-based intervention is not necessarily a result of parental skepticism, but may be due to the presence of other barriers (i.e., cost, distance, lack of awareness about the intervention's existence) impacting service utilization. Research conducted with a New Zealand sample found that the rejection of ABA-based services was significantly linked with a lack of awareness about the existence of these services (Shepherd et al., 2018). Therefore, a crucial first step in increasing service utilization, would be to increase awareness about ABA-based intervention. Findings from a recent study in Taiwan examining the effects of a low-intensity ABA-based intervention, also offer promising findings regarding parent utilization of these services (Lin et al., 2020). Although the study did not measure acceptability of ABA-based intervention specifically, the retention rate of Taiwanese parents remained at 100% over the course of six months (Lin et al., 2020). Furthermore, they found that, although parents were not prevented from using other services, very few parents sought additional services outside of ABA-based intervention (Lin et al., 2020). Taken together, these preliminary findings

from the current study and Lin et al. (2020) are encouraging and suggest that parents are open to ABA-based services and believe that they are helpful.

The most commonly used autism treatments were occupational, speech, and physical therapy, which are all services covered by the National Health Insurance in Taiwan. As expected, few parents in this study reported having previously used or were currently using ABA-based services for their child. Only one child in this sample was reported to have received intensive behavioural intervention (i.e., 20 hours or more a week for two years), with most children receiving very few hours a week of intervention for a short period of time. Important cues to action as endorsed by parents were recommendations from medical professionals, school, and other service providers. Distance, followed by cost, were primary logistical factors endorsed by parents in deciding on either medical treatments or non-medical interventions. These factors reported by parents are also consistent with the systematic review conducted by Carlon et al. (2013). These findings indicate the importance of medical professionals, school staff, and other service providers as information sources for parents. As a result, future programs aimed at increasing knowledge about ABA should also focus on involving physicians, other clinicians, teachers, and other key professionals who are important sources of information to help parents choose appropriate services for their child.

Objective 2: Comparison of Knowledge and Attitudes between ABA Users and Non-users

Parents' choice of ABA-based service use was found to be related to higher ASD knowledge, however, no relationship was found between parent beliefs about autism etiology and the use of ABA-based intervention. This finding contradicts the current limited research which suggests a link between autism casual beliefs and treatment selection (Al Anbar et al., 2010; Dardennes et al., 2011). There are several possible explanations for these results. First,

these differences in findings may be due to differences in research methodology. The previous studies (Al Anbar et al., 2010; Dardennes et al., 2011) utilized a structured questionnaire where parent participants were provided a list of 18 causes falling under one of three domains (i.e., personal, external, and hereditary) to rate on a 5-point Likert-type scale ranging from “Strongly disagree” to “Strongly agree”. In the current study however, parents were given an open-ended question to respond to, and answers were coded into one or more categories subsequently in order to facilitate statistical analysis. A main advantage of this chosen approach is that it allows parents to provide a response that best captures their own perspective. Secondly, previous studies examined the association of autism causal beliefs with several different treatment categories, whereas the current study examined one specific type of treatment. It could be possible that autism causal beliefs play a larger role with the selection of other types of treatments (i.e., medical or CAM treatments). The role of parent perception of autism’s cause in relation to treatment selection needs to be explored further in future studies.

As hypothesized, ABA-based service use was found to be associated with higher level of knowledge of ABA as well as more positive attitudes about the intervention. It is likely that parents who sought ABA-based services had a better understanding of ABA prior to choosing the service, and it is also possible that their experience with ABA-based intervention also increased their understanding and positive attitudes towards ABA. Based on the current findings, it is unclear the causal direction between knowledge and attitudes towards ABA-based intervention and further research, ideally longitudinal in nature, is warranted to better understand this relationship.

Objective 3: Predictors of ABA-Based Service Use

Findings from this study indicate that knowledge of ABA predicted treatment use over and above attitudes about ABA, knowledge about autism, and child characteristics. Many of the studies on autism treatment selection examine decision-making factors for multiple treatment categories (e.g., Al Anbar et al., 2010; Bowker et al., 2011; Dardennes et al., 2011; Green et al., 2006) and this is the first study that has examined multiple predictors for one specific type of treatment. Previously, it has been suggested that parents of children with severe autism are more likely to select ABA-based intervention (Bowker et al., 2011; Green et al., 2006). Although increased severity of autism symptoms (as indicated by higher SCQ scores) was found as the sole significant child factor, it was no longer significant once parent factors were added into the model. This is an important and encouraging finding as parent factors can be addressed through various knowledge mobilization methods. Given that parent knowledge about autism and ABA were both significantly related to ABA-based service use, knowledge about autism was entered at a separate step from knowledge and attitudes about ABA, in order to separate these effects. Given that the majority of parents in this sample had a university degree or higher, the sample was not representative, however, the results indicate that even with a high education background and high knowledge about autism, these factors are not associated with ABA-based service use. The finding that knowledge about ABA was the sole predictor of its treatment use, controlling for other parent and child characteristics, suggests that informing parents about ABA-based intervention may lead to an increase in service utilization. These preliminary findings are promising, however more research is needed to replicate these findings and to explore other factors that may explain substantial portions of the remaining variance. Furthermore, future

research on treatment selection should focus on specific treatments in order to better understand how knowledge of the particular treatment plays a role in the parent decision-making process.

Chapter 3: Qualitative Phase

Using semi-structured interviews, the second qualitative phase of this project focused on explaining in greater depth the results obtained the quantitative phase. This chapter begins with the specific objectives of this phase, followed by an explanation about the qualitative data collection procedures and analysis. The findings from the interviews are then presented, along with a discussion section.

Specific Research Objectives

The objectives of the qualitative phase were:

1. To understand how the predictor(s) of ABA-based service use contribute to or impede the selection and usage of ABA-based services; and
2. To explore other barriers and facilitators of ABA-based service use at the adopter, innovation, and systems level.

Methods and Procedure

Based on the results from phase 1, a semi-structured interview guide was developed. Parents of children with autism who had previously or were currently using ABA-based intervention were recruited based on their responses from phase 1. Other key informants working in the field of ABA and special education in Taiwan (i.e., ABA-based service providers, academics, teachers) were also purposively sampled through contacting local treatment centers and through personal contacts. Qualitative analysis was conducted as described by Ritchie et al. (2003) using the theoretical lens provided by the Diffusion of Innovations theory (Rogers, 2003). The Diffusion of Innovations theory was chosen as a way to provide insight as to how and why new ideas and/or innovations (i.e., ABA-based intervention in this case) are adopted by society.

Data Sources

Researcher's description

Throughout the research process, I kept a record of my thoughts and perspectives through memoing. Memoing is an important technique used by researchers to formulate developing ideas and to keep track of the decisions made throughout the research process (Birks & Francis, 2008). This process allowed me to consider the ways that my own background, experiences, and prior assumptions may influence the way I interact with participants and the conclusions I draw. In particular, I reflected on my own experiences in delivering ABA-based intervention in both Canada and Hong Kong and my broader clinical work with children with autism and their families. My experiences as a researcher, a clinician-trainee, and as an ABA-based intervention provider, provided me with various ideas about implementation strategies for ABA-based services, however, I also noted that I did not know enough about Taiwan in order to know whether these ideas were relevant or not. As an ethnically Chinese woman born in Hong Kong but raised in Canada, I saw that, while this offered me a unique perspective in understanding potential cultural differences, it could also bias me into seeing only cultural differences as a barrier to implementation. Furthermore, I was aware of my own position as an overseas-educated doctoral student examining a phenomenon occurring in a different region and was cautious about how I represented myself and this research to participants. In order to help minimize this influence, I sought recommendations throughout the study design process and during analysis from my committee member, Dr. Hui-Ting Wang, who is an expert in ABA-based intervention in Taiwan. Furthermore, with her help, I had a team of research assistants who were local students (WC and CL) and primarily responsible for conducting the face-to-face interviews with parents and professionals in Taiwanese-Mandarin. WC and CL were both senior undergraduate

research assistants with a background in special education. Neither WC nor CL had any experience with ABA-based intervention, however they both had goals to continue working with children with special needs and their families. Both were native Taiwanese-Mandarin speakers and could also converse fluently in English. Prior to the start of the study, I provided WC and CL training in conducting qualitative interviews and was present at the first few sets of interviews in order to address questions if necessary. There were no prior relationships between the interviewers with the participants in this study, although some of the participants were familiar with Dr. Hui-Ting Wang, due to her clinical and research involvement in the ABA field in Taiwan.

Participants

A total of 14 interviews were included in this data set, nine interviews with 10 parents (one interview included both the mother and father and they were coded together) and five with ABA service providers. Parent participants ranged in age from 38 to 51 years ($M = 44$; $SD = 4.36$). The majority of parents were biological parents, and all 10 parents self-identified as Taiwanese-Chinese. All parents had a university/specialist degree or above, and half of the participants were stay-at-home parents. Most of the parents had two children, with two families having both children diagnosed with autism. The children of the parents who participated ranged in age from 4 to 12 years old ($M = 7.67$, $SD = 2.91$). The majority of children had a confirmed (versus suspected) diagnosis of autism. Families were at different stages of ABA service utilization, with four families currently using ABA-based services, four families who had used but stopped services, and one family who chose to provide ABA-based services themselves.

The other key informants interviewed were comprised of various professionals including three BCBA-certified therapists, one academic, and one special needs teacher. Due to the limited

amount of ABA-based services and professionals available in Taiwan, description of all participants has been kept at group-level (i.e., reporting averages and range) in order to preserve confidentiality (Morse & Coulehan, 2015). Relevant characteristics (Morse, 2008) of parent participants are summarized in Table 2.1 and for professionals in Table 2.2.

Table 2.1

Participant Codes for ABA Users and Relevant Service-Use Characteristics

Code	Relationship with child	Service status	Frequency (hours per week)	Duration	Satisfaction rating*
P1	Mother	Active	5 to 7	2 years	Satisfied
P2	Mother	Stopped	≤ 2	4 to 6 months	Average
P3	Mother	Stopped	≤ 2	≤ 1 month	Satisfied
P4	Mother	Active	14 to 16	7 to 9 months	Satisfied
P5	Mother	Active***	2 to 4	≤ 1 month	Satisfied
P6	Mother	Active	2 to 4	3.5 years	Very Satisfied
P7	Father & Mother	Stopped	5 to 7	4 years	Very satisfied
P8	Stepmother	Stopped	2 to 4	4 to 6 months	Average
P9	Father	Active**	N/A	N/A	Average

*No parent in Study 1 provided a ‘not satisfied’ response

**Just started ABA services less than a month earlier

***Took ABA-based courses to provide therapy at home and the frequency and duration describes the course length

Table 2.2

Participant Codes for Professionals and Relevant Characteristics

Code	Overseas Training	BACB credential	Role
A1	Yes	Yes	Service provider (therapist)
A2	No	No	Special Needs Teacher
A3	Yes	Yes	Academic Instructor
A4	Yes	Yes	Service provider (Management-level)
A5	Yes	No	Academic Professor

Participant Recruitment

Ethical approval was obtained from York University's Human Participants Review Committee. Parent participants were recruited based on their participation in study 1. Participants

in study 1 were recruited via convenience and snowball sampling and were parents or caregivers of a child up to the age of 18 with the diagnosis of autism or suspected autism and currently living in Taiwan. If participants in study 1 answered “yes” to having received ABA in the past or to currently receiving ABA, they were invited to leave their contact information to partake in semi-structured interviews. A total of 36 participants who completed the survey in study 1 met criteria for participation and 28 participants provided their contact information. Interested participants were then contacted and provided with the study information either via email or by phone. Nine parents were unable to be contacted despite several follow-ups, two declined to participate due to being busy, and four initially agreed to participate but were unable to schedule an interview time. Despite multiple attempts to discuss and confirm that parents met the requirements to participate in the current study (i.e., inviting participants based on survey responses and discussing the nature of the study with interested participants beforehand), four of the interviews were excluded from this dataset as parents did not meet the inclusion criteria of having received ABA-based services.

Other key informants, referred to in this study as “Professionals” (i.e., teachers, educators, consultants, board certified and non-board-certified ABA therapists), who deliver ABA-based services in any capacity were also contacted to participate in semi-structured interviews to better understand factors that affect ABA-based service utilization in Taiwan. These professionals were recruited via contacting all four agencies providing ABA-based intervention, through the Taiwanese ABA association, and through personal networks. Seven professionals expressed interest in participating in the study, however two later declined to participate.

Although eligible parent participants were recruited via convenience and snowball sampling methods, the final dataset included interviews which were purposively selected due to unique participant characteristics. This was done in order to provide a range of experiences from service users and service providers. Parents were selected for interviews based on the answers provided in study 1: 1) whether they are currently using or have stopped using ABA and 2) range of satisfaction with ABA services. ABA service providers were selected to reflect a range of ABA training and to represent different roles in ABA service delivery.

Data Collection

Based on the data from part one as well as from discussions with a local expert working within the field of ABA, a semi-structured interview guide was created (see Appendix C). Interviews were conducted either in person, by phone, or by webcam. Of the nine interviews, eight were conducted in Taiwanese Mandarin by WC or CL, and one interview was conducted in English by the first author. Interviews lasted between 20 minutes and 1.5 hours, with an average time of half an hour. Participants who completed the interview were compensated with a \$6 (CAD equivalent) voucher. All interviews were audio-recorded, and then transcribed and translated directly into English by research assistants proficient in both languages.

Data analyses

Analysis was conducted using the framework approach which was developed by Ritchie et al. (2003), and outlined by Gale et al. (2013). This approach was developed for conducting applied qualitative research, where the findings are used to answer specific questions that lead to actionable changes (Ritchie & Spencer, 1994). In the first stage, I debriefed with each of the research assistants post-interview to summarize the interview and to obtain their initial impressions and thoughts. This was particularly important as the majority of the interviews were

conducted in Taiwanese Mandarin, and it was through this ongoing debriefing process that I was able to gain a better understanding about the context and certain nuances that could not be picked up through reading the transcripts alone. For instance, some parents explained that they lived in a certain geographical area and the local interviewers would realize that this was an area that was quite far from the city and had fewer services available. Therefore, they were able to tailor their questions to address these experiences.

In addition to debriefing with the interviewers, I also immersed myself in the data by first reading all transcripts and memos, and then identifying recurring concepts and ideas. Through a process known as open coding, transcripts were read line-by-line and a code (i.e., a label or paraphrase) was given to concepts or ideas that were considered to be relevant. The purpose of coding is to classify all data so that it can be compared to other parts of the data set (Gale et al., 2013). After coding several initial transcripts, codes were then grouped together into broader categories that explained similar or interrelated ideas. In the early conceptual model, the categories were: 1) “Quality of ABA-based services” comprised of difficulties related to service provision 2) “Internal characteristics of ABA-based intervention” captured feelings and experiences participants had about ABA strategies and 3) “Logistical barriers to ABA-based services” encompassed difficulties related to finances, time, and geographical distance. These initial categories and codes were used to create a working analytical framework which was applied to subsequent datasets and was further refined by the addition of missing codes and categories. A framework matrix was then used to summarize the categories in order to identify and explore different patterns and to generate themes and sub-themes.

The Diffusion of Innovations theory (Rogers, 2003) was chosen as an explanatory framework to better understand the patterns in the thematic chart, and it also allowed for further

coding themes to be derived. In order to ensure that the explanatory framework did not force a fit with the original data, this framework was applied at a later stage of the analytical process to see if a match occurred with the framework matrix. By applying this theoretical framework, an additional theme of ‘Adopter Characteristics’ was developed in order to highlight internal factors that lead parents to begin, continue, or stop ABA-based services.

Similar to quantitative analyses where the strength of the study is determined in part by the validity and reliability of the measures, establishing rigor (also known as trustworthiness) in qualitative analyses is achieved by meeting several criteria (i.e., credibility, transferability, dependability, and confirmability) (Lincoln & Guba, 1985). Credibility of the findings, which refers to representing the truth of the data, was enhanced through spending 4 months living in Taiwan and interacting with local ABA-based professionals and researchers, and engaging in ABA teaching activities. Checks were also completed throughout the interview process by debriefing with interviewers. Translations were also checked to ensure that the English version captured the nuances and context of the original Taiwanese-Mandarin interviews by comparing the notes made post-interview with the translated transcript. Member-checking, where the summary of the themes is presented to participants for feedback, is also a common way to enhance credibility of the findings, however some authors have criticized the use of this method stating that study results are often based on multiple perspectives, and it may be difficult for a single respondent to identify their own view (Morse et al., 2002). Furthermore, if the study’s findings are changed to be more aligned to specific feedback, this would only serve to decrease the accuracy of the data (Morse et al., 2002). As result, it was decided that member-checking would not be used. Other strategies, however, were used to enhance the credibility of the study’s findings, principally data triangulation, which is the process of using multiple sources from

which to draw conclusions. This was conducted across methods (i.e., using both quantitative and qualitative phases) and across researchers (i.e., with a Canadian expert in autism and ABA and a Taiwan expert in ABA and with graduate-level researchers in an autism lab). Transferability refers to the generalizability of the data, and this was done by providing thick (i.e., in-depth) description and giving quotes wherever possible in order to remain close to the original data. This enhances the generalizability of the data as it allows future researchers who wish to transfer the data, to be able to judge the suitability of the transfer (Lincoln & Guba, 1985).

Dependability is concerned with providing a clearly documented trail that provides transparency in the research process. Typically, this is done by keeping records of raw data, notes, and reflexive memoing, such that other researchers, through going through the audit trail, would be able to draw similar conclusions (Koch, 1994). An audit trail complete with raw records, notes, and memos were used to document this study.

Confirmability refers to the idea that the interpretations and findings from the study are clearly derived from the data. In order to do this, theoretical frameworks, methods and analytical choices must be clearly described throughout the study (Koch, 1994). This was achieved through explaining the data collection and analysis process thoroughly within this section.

Results

A total of 375 initial codes were grouped into nine categories that fall under the three overarching themes as proposed by the Diffusion of Innovation framework: (a) Adopter characteristics, (b) Innovation characteristics and (c) Outer environment characteristics (see Table 2.3). The adopters are parents who have selected ABA-based intervention, the innovation refer to ABA-based intervention, and the environment refers to the healthcare and societal structure of Taiwan. A common thread underlying all three themes was a lack of knowledge

about ABA. Each of the themes and sub-themes are described in further detail below. Participant codes and either their ABA status for parents (i.e. Active or Stopped) or BACB status for professionals (i.e. BACB or non-BACB) will be indicated next to each quotation.

Table 2.3

Main Themes and Sub-Themes

Diffusion of Innovations Theme	Sub-themes
Adopter Characteristics	○ Obtaining Information about ABA ○ Enrolling in ABA 101 ○ Persisting through the Process
Innovation Characteristics	○ Balancing Business with Healthcare ○ Misunderstanding about Specific ABA strategies ○ Needing to Normalize ABA strategies within Chinese Culture
Outer Environment Context	○ Competing with “Good Enough” Services and Other Private Therapy Options ○ Needing Greater Interprofessional Collaboration within the Education System ○ Lacking a Professional Identity

Adopter Characteristics

Although each family had their own unique pathway in selecting ABA-based intervention for their child, there were three checkpoints that acted as either barriers or facilitators for parents in choosing and continuing with ABA-based intervention.

Obtaining Information about ABA

When describing how they first found out about ABA, parents in the sample reported numerous types of information sources and pathways. Information sources included medical professionals, schoolteachers, other parents, websites, and books. Teachers in particular, were an important source of information. One parent explained:

Usually the teachers at school would give us information about early education intervention. My child is currently in elementary school, so the elementary school's resource section teacher would give us advice on some courses to take, and then we would go try them. (P2, Stopped). Similarly, a special education teacher also explained that, in her experience, parents relied heavily on information from schools:

For the students that I provide service for in [region], of the cases I have handled for 7 years, no parent has ever told me that they had looked for this type of resource before [referring to ABA]. This is mostly done through the schools. The good thing about Taipei and New Taipei is that almost each school has their own professional special needs teacher and they rely heavily on the teachers to find resources. (A2, non-BACB)

Often times, parents heard the same recommendation of using ABA from different trusted sources, which sparked their own curiosity about ABA. However, some parents felt that the information they received from professionals was conflicting: "When we confirmed the diagnosis at the [local] hospital, we got mixed messages. Some of the staff would recommend ABA, but others said it was not necessary". (P6, Active) Online parent support groups were a particularly important source of information with most parents in this sample connected via a social media group. One of these online groups included roughly 500 other parents within the local region, and parents often share their experiences with different services through these group chats.

Two of the families in this sample had roots in the United States and in Canada and explained that they were already familiar with ABA services prior to moving to Taiwan. Both these families were also able to read and understand English. One parent stated:

The doctors in the US told me that they believed that my child had the common symptoms of autism. So, we researched on the internet and we read books and we found that applied behaviour analysis is backed by real evidence. So in Taiwan, we searched for similar organizations. (P1, Active)

This was consistent with observations made by ABA key informants, who explained that knowledge of English facilitated parents in finding out about ABA as there is much more information available in English:

In my perspective, the parents who have a better understanding are those who are well-versed in English and they will read the English literature and reports. They will know this this is good and that it is effective and they will invest in it but if they search for the information in Chinese, then they will have a more skeptical attitude. (A1, BACB)

Enrolling in ABA 101

The majority of the parents in this sample reported learning more about ABA. This ranged from learning via online videos, to attending 1-day workshops, to attending ABA sessions with their child and to completing six months of courses. For some parents, learning more about ABA felt like a necessity as they initially could not access ABA-based services directly for their child due to waitlists. As a result, they took classes for the purposes of using ABA strategies at home. For other parents, they chose to further their own knowledge about ABA because they could not afford more ABA-based intervention per week. For instance, one parent explained that their child was currently enrolled in ABA-based services twice a week, which was already very expensive. As a result, she wanted to learn more about how to continue to implement ABA strategies at home:

[The cost of ABA-based services] gave me a lot of pressure and I felt that for two days a week, they are there at [the ABA centre], but after these two days, they are at home for four days and there was no way to use the methods that the teachers gave us at home because things are different at home. I discussed this with the teacher, but at home it is not like in a simple classroom with just a teacher and a student- there are other things, and other people in the home environment and there are a lot of things that distract them.

(P8, Stopped)

For another father, he decided to take an intensive 6-month course in order to provide ABA-based intervention at home for his child:

When the youngest was about 4 years old, I personally became more familiar with ABA because he did not talk. I sincerely hoped that he would learn to speak so I attended a few courses and ABA was a critical part of it. Since then, we did ABA-based instruction at home. (P9, Active)

A few parents explained that they would want to learn even more about ABA and felt disappointed that there were very few local services that could provide them with a comprehensive understanding of ABA. One parent explained that:

I think the best way for parents is to be able to master this skill, the best thing is that you can practice it with your child from the time they get up till the time they go to bed.

(Laughter) Yeah, but there is no such institution in Taiwan, that is, to tutor or supervise parents. (P4, Active)

Other challenges related to parent ABA education were scheduling conflicts, as many of the workshops offered were during the typical 9 to 5 work hours, making them inaccessible for working parents.

Parents also discussed feeling frustrated about the ABA education they received. Often times, they felt that it was hard to apply the knowledge they had learned from books and workshops to real life situations. On the other hand, parents also felt that learning more about ABA provided them more confidence to communicate with their therapists. Furthermore, parents found that they became more confident in their own parenting skills, especially when parenting their child in public situations. One parent explained that:

There are “observers” who try to help and they tell you what they think [you should do], but now you have more ground to stand on so that you can explain to these observers that it is not the situation they think it is. (P9, Active)

Similarly, all professionals expressed the need to educate parents about ABA to ensure that the progress made during ABA sessions is continued at home. Not only was it important to educate parents, but also grandparents as well, as many families in Taiwan have three generations living within one household. One professional explained that while parents are usually understanding and will continue to practice ABA strategies at home, there is a greater difficulty with grandparents:

[Grandparents] usually think ABA therapists are like home tutors, who come once a week, so when this week’s class is done, they wait for next week. But in fact, ABA-based intervention requires intensive practice, so if the family members treat this as a home tutoring service, and the child is not trained outside of class time, then there won’t be a lot of improvement. (A3, BACB)

Persisting through the Process

Although parents in this sample had gathered information about ABA, much of the knowledge was on a theoretical level. The parents’ narratives suggest that while having

knowledge about ABA is important, it is not sufficient for having parents continue with ABA-based intervention for their child. Parents needed to have a clear expectation about intervention outcome in order to persist with ABA therapy.

When describing their initial experience with ABA-based intervention, many parents spoke of blindly following ABA principles and not knowing whether this would lead to improvements in their child. One parent took parent ABA courses based on the recommendations from the social worker:

I started the parents' class from October last year to November... I took the basic courses first, and advanced courses later. The courses ended in January this year. After finishing the courses, I've been wondering if this ABA would work or not? I honestly had no idea at that time. (P5, Active)

For parents who just started ABA for their child, they wondered about whether their child would make progress. “It’s been just over a month. So far, they just taught my kid...well, for example, they required my kid to point things out, and to match. They didn’t teach him anything else. I think their teaching progress has been too slow.” (P5, Active) Parents discussed “tolerating” the first few months of ABA-based therapy and not being sure about their decision to continue:

It was very hard for me to handle [ABA-based therapy] since my child cannot communicate with me, and I felt uncertain. In the beginning, we attempted it for a long time without any significant sign of improvement. I wondered if there was a need to continue. We endured and when we discovered the minor changes we saw in the progress reports-we felt relieved. We realized we cannot rush and we need to take it slow. The worst was the first year. (P9, Active)

Similarly, another parent who has had ABA-based therapy for her son for 4 years, explained her thoughts in the beginning: “Even after starting ABA for 3 months, my feeling was so-so and my son was still very unwilling to imitate sounds or words.” (P6, Active) Parents would often give themselves an arbitrary timeline to see if there would be improvements for their child, prior to deciding to stop the intervention. In the meantime, they looked to other children in the class or to the experiences of other parents as a source of motivation to continue with ABA-based intervention.

Professionals also noted that parents often began ABA-based intervention thinking that improvements would be seen immediately and explained that some parents would feel frustrated with the progress:

There are some parents who are eager to see improvements and results. If I work on something with the child today, they would ask if the situation will be better tomorrow. But every child has a different level of disability and they show different levels of improvements. One reason could be that [the parents] don’t want to believe the fact that their child has a disability, and another is that they think ABA is not a good thing, so they treat us like medicine, that is fast-acting and instant relief. As the child ages, the parent often gets used to the situation and won’t be in such a rush. (A3, BACB)

Parents who have used ABA-based services for a long duration of time, spoke about the improvements in their child and that seeing the results first-hand helped them with continuing with the therapy:

There was a big change. Before, there was a lot of behaviour, a lot strange behaviour and now after ABA, there is less and less. Of course, it is impossible to have none but there

are less and less and now they can attend classes with other typical children. (P7, Stopped)

Often times, parents explained that the improvements were pointed out by other family members and friends, which also served as reinforcement for parents to continue with ABA-based therapy:

Actually in the parents' view they cannot see it as clearly but, for example, a relative that you only see every few months, they can tell you clearly that there is a big change from before. Others can see the change, even friends will sometimes mention that the child has improved quite a bit in their speech and language skills from before. Actually, we needed a longer period of time, around half a year before we saw a significant improvement and that's when we were able to see that the ABA therapist they are currently seeing is suitable for them. (P1, Active)

Innovation Characteristics

Both parents and professionals shared their perceptions of ABA-based services provided in Taiwan. Specific characteristics of the intervention and service delivery model were discussed as potential barriers to service utilization.

Balancing Business with Healthcare

ABA-based services in Taiwan operate on a business-model and parents pay for ABA services privately. While some were able to get reimbursed by private insurance, others were unable to. As such, the financial cost of ABA was one of the biggest challenges to starting and continuing with ABA services. One parent explained that she had to stop services due to financial reasons:

The costs were getting a bit stressful for me...because they charge 700 NTD (~\$32.50 CAD) an hour and that is almost 20 thousand (~\$930 CAD) a month. So after about close

to half a year, I felt that this was financially getting stressful. The road forward is still very long and with this in consideration, [...] I stopped ABA-based intervention when we reached our spot on the waiting list for the [government-funded] therapy at hospital. (P8, Stopped)

On the other hand, however, although cost was a barrier to services, it was also one of the ways for parents to gauge the quality of services offered. Some parents questioned the quality of centers that were able to charge a lower fee:

So, the institution that we were at... the fee of [that ABA centre] is the cheapest one so far among all the other institutions. So, I have no idea about the quality of their teaching. But in the Taiwanese ABA market, this is the lowest price. There are expensive ones as well, the most expensive one that I have known is three times the cost [of the one I am currently at]. For this kind of service, they require you to go to the ABA therapist's house and they have senior therapists. (P5, Active)

Many of the ABA centres offered 'trial classes' and both parents and professionals had mixed responses towards this practice. One parent described the experience as feeling pressure to pay for services and likened the feeling to paying for a "cram school"¹: "It's like they ask you to take a trial course, and offer all kinds of courses, and then they talk about how much all the courses cost. Yeah, to me, it feels very commercialized." (P3, Stopped) For other parents, they welcomed the "free" classes:

If they told me that I could try a few lessons for free, of course I would give it a try. No matter how far the place is. Then I can see whether my child will get any improvement

¹ Specialized tutorial centers that are popular for many schoolchildren in Taiwan. Top-quality cram schools are often expensive.

from these lessons. If there was any progress, we would consider it as a choice. Although it might be expensive, as long as it is effective, we will try it. (P4, Active)'

Professionals also felt torn about the cost of ABA to parents:

There is no assistance of any sort [to parents], there is no [government-provided] insurance. There are times that we provide discount for low-income families and a lot of parents signed up for that. Some people need services, but they can't afford it. We provide with a month of free class, they wish to continue, but they can't, then they are forced to go back to hospital system again, which is very realistic. (A4, BACB)

The concept of trial lessons however, creates an expectation of observable progress within a short-time period. For professionals, this was a particular difficult dichotomy to address:

Parents pay a large sum from their own pocket and therefore, they want to achieve certain outcomes. [...] This field cannot be entirely profit-based because of this. Progress depends on the ability of the child, but to a parent who pays the money, they feel the price-performance ratio is rather low. (A4, BACB)

As a result, many parents would try different ABA centres for short periods of time, before changing to another centre, in hopes of seeing improvements in their child.

Since parents were paying a large amount of money for ABA services, many also wanted to know what they were paying for. While some ABA centres allowed for parents to observe, others did not allow parents to come in. Parents who were not able to observe sessions noted that they were disappointed, but at the same time, they were also understanding that the centres did not want parents observing to affect the child's behaviour: "For me, I want to observe my child so when I am not allowed to, this is a negative experience even though I understand their reasons. Still I feel unhappy about this." (P9, Active) Another parent also explained:

We were not allowed to watch [the sessions] and some of the parents would be like “Oh, so I just drop of the kids for 3 hours for a day and that’s \$3,000 (~\$140 CAD)? What are they doing there?” and we also had these types of concerns in the beginning, but I decided to trust in the professionals. (P6, Active)

Misunderstanding about Specific ABA Strategies

Although all parents in this sample chose ABA-based intervention, there were aspects of ABA therapy that parents were unclear about that made parents question their decision in continuing with ABA-based intervention.

In describing their perception of therapy, parents commonly used the words “rigid” and “structured”. For instance, one parent explained her frustration with task analysis:

They want every step from you and according to their rules. I was pretty confused about it, like, is it necessary to take the Velcro off your shoes first and then take off the shoes?

Or is it okay to take the shoes off, right from the heel of the shoes? (P5, Active).

For another parent, they wondered whether the constant repetition of basic actions would lead to their child having low esteem as their child would think that they were not capable of doing more. Similarly, ABA professionals also found some of the current ABA therapists were “too rigid” in their delivery but that this was due to lack of training rather than the therapy itself. One professional noted that:

I think ABA is very flexible, and there can be up to about 100 different types of strategies. [...] An effective ABA treatment plan cannot stick to one rule, and it needs to be used flexibly. The same technique can have different results with different people. If you are skilled, you can get good results, and it will be very effective when used with

individuals with developmental disabilities. Conversely, if you are not proficient, it will be frustrating to use. (A3, BACB)

Parents were also surprised about aspects of ABA that appeared to be simple, and similar to activities they were already doing with their child. For one parent who had just started ABA-based services at the time of the interview, she wondered:

Why would they teach something that I think we could teach by ourselves at home, something like naming the objects? [The ABA therapist] used a lot of cards to teach my kid about how to name them. But the objects that they were naming was already something that had done before. (P5, Active)

The use of a high-probability sequence (i.e., an ABA strategy used to increase motivation by completing easier tasks and being reinforced, to build momentum for a more difficult task) by ABA therapists was also confusing, as many parents pointed out that their children already knew how to do many of the skills the therapist was requesting.

Although majority of the parents felt that ABA was effective, parents were worried that their child would only learn how to copy a behaviour, without a real understanding as to why the behaviour was needed. One parent explained that she had discussed ABA therapy with a therapist in a medical institution who felt that ABA was good, but the therapist had likened the training to “being just like being a robot, it’s like you’re just commanding children to do whatever you want them to do. It makes them less likely to have their own ideas.” (P3, Stopped) Similarly, another parent explained feeling mixed emotions about his child’s progress in ABA: “When they keep repeating and practicing the same thing, I wonder whether [my child] is just memorizing the repetitiveness or if they are actually able to use it?” (P6, Active) Other parents

also felt that ABA was useful for teaching basic skills but would not work for teaching interpersonal skills. One mother explained:

Many [of the other] mothers shared something like, if a child was restless or just couldn't sit there quietly, they said that they could use ABA. For me, I think, if I wanted to try [another therapy], it would probably be RDI, which is more about interpersonal interactions. Or maybe the one with floortime. (P3, Stopped)

Needing to Normalize ABA Strategies within Chinese Culture

The idea of understanding the function of behaviour, which is the central concept of ABA, was particularly difficult to accept for those unfamiliar with or new to ABA. Within traditional Chinese culture, there is the idea that children are to be obedient and follow their parents' rules. When a child is acting out, punishment (i.e., hitting, removal of toys) is considered to be acceptable. In ABA however, it is crucial to understand *why* the behaviour is occurring, and to develop a strategy to reinforce a more acceptable behaviour to replace the problem behaviour. This was a difficult concept for professionals to explain to parents who were considering ABA-based intervention, and it was also difficult for parents in this sample to explain to relatives, friends, and members of the public. One parent discussed the difficulty of using ABA strategies in public:

For example, our son will run and jump around and when we were out for breakfast, there were some very concerned elderly ladies that came to us and told us "you should not teach your kids like that, you should hit them". (P9, Active)

While many parents struggled with certain characteristics of ABA, a subset of parents felt that the concept of ABA could be applied not only to other children with autism, but to all types of children. These parents were able to identify principles of ABA occurring in their own lives

(i.e., use of reinforcement), such as working and getting paid, which allowed them to realize ABA strategies were not limited to “severe cases only”. One parent stated that: “I think that a lot of people feel that ABA is very unique but I feel that our surroundings and lifestyle all include ABA.” (P6, Active) These parents felt that learning ABA provided them with parenting strategies, and that they used similar methods for their other children. One father explained the similarities between teaching his child to ask for food to how his own parents taught him while growing up:

For example, say he wants an apple but we do not give it to him unless he says what we ask him to. In this case, what he wants is clear and there is no confusion. So when it is clear that he wants it, we can use behaviour analysis to achieve clear results. Even when I was growing up, this method was used both intentionally and unintentionally. Personally, my parents have done something similar to me in the past. (P9, Active)

Professionals also felt that the technical terminology of ABA made it difficult to convey important concepts, which fuels negative impressions of ABA being a “highly repetitive, dull and animal-like” training method. One professional pointed it out: “It’s not necessarily the language barrier, because ABA has created its own terminology. But more terminology makes it difficult to communicate with the society or with other professionals who are not in the field.” (A5, non-BACB) Similarly, professionals felt that it was important to normalize ABA strategies through linking concepts to real-life situations when communicating with parents and other non-ABA professionals. For instance, one professional explained that, when discussing the importance of reinforcement to teachers, many initially did not want to use it. However, “in some situations, they were already using it without knowing it- things like simply looking at the child,

or giving points are all rewards[...]we just need to add to it by helping them address specific problems.” (A3, BACB)

Outer Environmental Context

Many of the barriers toward ABA-based services use occur at a systems level. Specifically, ABA-based services in Taiwan often compete with existing services provided by the public and private system. ABA-based service providers also felt a lack of legitimacy due to a lack of standards regarding ABA quality. In addition, professions providing ABA-based services often found it difficult to integrate with existing services provided within the education system. As a result, many of these systemic limitations lead ABA professionals to feel like they are “working in secret”.

Competing with “Good Enough” Services and Other Private Therapy Options

Currently in Taiwan, the national health insurance provides early intervention services, which include occupational, speech, and physical therapy, for children prior to elementary school age. The quality of the current system is “not very good but good enough.” (A5, non-BACB) As a result, many professionals felt the existing service system was a large competitor for ABA-based services, especially for families with financial difficulties. “I have faith in the quality of our [ABA]service, but if the quality costs the parents 20 times more, the competition is certainly difficult.” (A4, BACB) Current hospital services do not face the challenges of financial costs, distance barriers, and availability as do ABA-based services.

Many parents in this sample explained that they decided to try other services when they felt that the early intervention services were not enough or when their child was no longer eligible for the services due to age. Some parents felt that, in comparison to the speech and

occupational therapies traditionally offered by the government, ABA-based services focused on the core characteristics of autism. One parent explained:

In terms of occupational therapists, they will usually focus on mechanical movement and control of their limbs only and speech therapists will focus on sound and pronunciation.

So I believe these therapies are only supplemental. I think I mainly use ABA as the focus for our therapeutic treatment plan. (P1, Active)

However, parents were not only limited to ABA as a potential option. Parents discussed an array of other services that they considered in addition to ABA-based intervention, such as music therapy, animal therapy, and acupuncture. One parent explained that the biggest barrier to choosing other out-of-pocket options was mainly the high cost:

I heard some from other parents that sound very skeptical. For example, using certain types of light, phototherapy and such but each time cost several hundred thousands of dollars. Some weird light because they say that the children's brain structure is different so they need some special light. This is something we have not tried. If we were not under financial stress or we were very wealthy then this is something that we would try but we need to consider the reality of our situation. (P6, Active)

Needing Greater Interprofessional Collaboration within the Education System

Within the school system, children usually have access to special education teachers and other behavioral supports. Since 1979, all special education teachers in Taiwan have been required to undergo training in basic behavioural principles (Ministry of Education, 1979). For parents with school-aged children in this sample, many felt that additional ABA-based services would be helpful within the classroom settings. However, it was often difficult for them to have their ABA therapist be allowed in school. One family explained:

When our child was in Grade 1, we asked the ABA teacher to help with integrating into the school. At that time, it was to have the [ABA therapist] at school for 3 hours a week, because our child did not know how to make friends. So we asked [the ABA therapist] to help him integrate into the group. This was actually quite helpful, but it created a different problem. That is to say, some teachers at the school were not willing to accept this, to have someone else interrupting them in their class when in fact they are not. Some of teachers at the school felt that this was an obstruction in their class while other teachers were more open and saw this as a sort of aid. I found that kindergarten teachers were more likely to find this as a sort of aid, while the elementary school teachers did not. (P7, Stopped)

Similarly, ABA service providers also felt that mainstream schools were often not familiar with ABA, and even when they were allowed to work with the child in the school, they faced many barriers in working with the classroom teacher. One of the barriers discussed was the definition of a “problem” behaviour. One professional explained:

In Taiwan, if you don’t sit quietly in class, this would be called a problem behaviour. But in the US, a child can still be paying attention in class even if he doesn’t sit quietly in class, or lies on the ground or stands by the wall. So, you need to make the decision [of what is a problem behaviour] to either benefit the teacher or the child. (A3, BACB)

As a result, ABA service providers often had to work with teachers in defining the problem behaviour, and in implementing ABA strategies that would benefit both the classroom and the child. ABA professionals also shared that teachers often did not understand why the child was getting “preferential” treatment- for instance, getting rewarded for participating when other children are not. ABA professionals explained that a large part of their work within schools was

to educate classroom teachers about ABA strategies, and the collaboration between the teacher and the ABA professional often improved after teachers understood more about ABA.

Lacking a Professional Identity

Unlike occupational and speech therapists who are required to undergo a training and certification process, there is a lack of a similar process for ABA therapists. As a result, the title of “ABA therapist” encompasses various levels of training, ranging from receiving a certification for a 1-day workshop to receiving BCBA certification, which requires extensive graduate-level courses, 1500 hours of supervised therapy, and a written exam. Without an official designation, it was up to the parents themselves to decide whether they felt the therapist was qualified or not, and parents often spent time and money to change therapists. When describing their current therapist, one parent explained: “I think they are not better than me. (laughter) But sometimes I would tell myself that I just bring him there, having him play with someone twice a week.” (P5, Active)

Similarly, professionals were frustrated with the range of quality found in those providing ABA services:

I believe the situation in Taiwan right now is not good. There are some people who have received ABA training but have not yet gotten certification. I feel that those with professional certification are better because they adhere to a code of ethics but there are some who have just learned a little of the techniques and have not intention to get professionally certified who still promote themselves as being able to use ABA and end up offering this service. (A1, BACB)

Four of the five professionals in this sample received their ABA training overseas, and many noted that part of the issue was that there were few university-level courses on ABA in Taiwan.

Due to a lack of requirement for official certification, professionals also explained that many current service providers did not feel a need to gain more training. Furthermore, the ABA professionals who are highly qualified and have the BACB certification end up leaving to places such as Mainland China, where a professional designation is recognized and valued. Current ABA professionals also felt torn between staying locally and moving abroad. One professional explained: “To be frank, it is hard to work in Taiwan, you can’t support the family with this, so it’s better to go other places. But people in Taiwan also need this service, there is nothing you can do about it.” (A4, BACB)

Although a majority of parents and professionals felt the need for a certification system, certification through the BACB was not necessarily the answer. Professionals noted that the high cost and length of time required to obtain a “Western certification” from the BACB was not practical given the current high demand for ABA services. Furthermore, although the BACB credential is recognized internationally, very few parents in Taiwan know the value of the credential:

If everyone agrees [to the BACB system] then there is no problem [...] but this current system is not one that everyone understands and we need to remind parents when they go to receive ABA services, they need to ask if they have the appropriate supervision and certification. (A1, BACB)

Another professional also felt that the BACB certification provided experience for foreign healthcare systems where ABA is covered by private insurance but does not prepare professionals to work within the Taiwan system where ABA services are paid for primarily out-of-pocket.

Discussion

Phase two of this study examined the perceptions of key stakeholders in the utilization and provision of ABA-based intervention in Taiwan. Using the Diffusion of Innovations framework, this section of the study provides insight on the specific barriers that parents and service-providers face in the adoption and implementation of ABA-based services in Taiwan. Participants in the current study described a convoluted path to obtaining ABA-based services, with multiple barriers existing at all levels of the system.

At the adopter level, it was clear that parents in this sample wanted to obtain more knowledge and training in ABA, but many found it difficult due to the limited amount of information about ABA-based intervention in Chinese. For parents who had a knowledge of English, they were able to access English material, however, parents and professionals reported that there are limited resources available on ABA in Chinese. Although several textbooks discussing ABA are available in Chinese, many of these textbooks are marketed under different labels (i.e., evidence-based interventions, communication training) rather than ABA or are specific for ABA professionals (i.e., the Chinese translation of Cooper et al., 2007), which may make it difficult for parents to search for and understand this information. Thus far, only one systematic review has been conducted for both Chinese and English studies on ABA-based intervention for children with autism (Liao et al., 2020). This review specifically focused on Mainland China and found only 35 studies. Taken together, these findings suggest a need for more information on ABA to be translated and adapted for the Chinese population, and specifically for Taiwan, and for information resources to be clearly labeled as ABA, so that parents and other professionals can be introduced to ABA-based intervention.

A key finding in this study is the high level of parent involvement in ABA-based intervention. All parents in this study discussed the importance of learning more about ABA in various capacities, however, many of them were limited by the lack of availability of parent-training courses. One of the primary motivations for parents in this sample to become personally involved in learning about ABA, was due to the various difficulties (i.e., financial, time, waitlist) in obtaining high intensity services in Taiwan. This is consistent with findings from Mainland China, where parents have been found to also take a central role in their child's ABA-based intervention (Liao et al., 2018, 2020). Similar to Taiwan, ABA-based interventions are also paid for privately and there is a shortage of qualified professionals in Mainland China (Wang et al., 2013). As a result, parents often take on the role of a therapist in order to deliver ABA-based services to their child. Given the motivation of these parents to become more involved in ABA-based intervention, it is critical that more parent training and coaching is given.

At the innovation level of the model, participants' views were consistent with prior research on the negative perception and misunderstanding surrounding ABA-based intervention. Many of the common misperceptions surrounding ABA-based intervention in the West (Keenan et al., 2015) were also discussed as barriers by the parents and professionals in this sample. Much of the negative perception regarding ABA-based services is fueled by the terminology used within ABA (i.e., the use of words like punishment and discrimination to describe methodology) (Bailey, 1991; Critchfield et al., 2017). This suggests that the translated terminology contains many of the same negative connotations as the English ABA terms. The results highlight that effective implementation requires a need to address the misunderstanding surrounding ABA strategies by explaining commonly used methods in relatable terms and providing examples that are applicable to daily life (Freedman, 2016).

The out-of-pocket service delivery model of ABA-based interventions also meant that the financial cost was a large barrier for parents. As a result, many of the parents in this sample received low intensity (i.e., lower frequency and/or lower duration) ABA-based services. Given these barriers, a recent study by (Lin et al., 2020) examined preliminary outcomes of a specific ABA-based intervention adapted specifically for the Taiwanese public health system. The preliminary results from a low-intensity ABA-based intervention show promising outcomes, with children showing significant improvements in language and cognitive functioning, and more research is needed to examine whether children benefit from such lower intensity ABA-based services.

The results of this study suggest that outer environment level variables also play a critical role in the provision of ABA-based intervention. Currently in Taiwan, early intervention services are covered by the national health insurance. These service providers often also have a certification, a degree, or a license, which can serve as a quality indicator. For ABA-based intervention however, therapists do not undergo a similar process and as a result, there is a wide range of quality. Although quality was an important variable for parents in this sample, the lack of a certification process meant that parents had to use subjective measures of ‘quality’, such as cost, subjective improvement, and quick results as indicators of how effective the treatment was. For ABA-based interventions, however, these are unlikely to be a valid quality indicator and may even hinder progress as parents often find themselves trying out many different places but not allowing enough time to have progress occur. The lack of certification process was also a source of frustration for service providers and many explained that they had colleagues who had left Taiwan in order to pursue a career in Mainland China, where having a certification was recognized. The recent change in BACB certification also serves to compound this issue of

legitimization as the BACB has announced that it will no longer certify applicants outside of the U.S., Canada, and the U.K after the year 2023 (BACB, 2020b). Although countries may apply for country-specific re-instatement, discussion from parents and professionals in this sample suggest that a local certification process may be better suited to address the specific needs of Taiwanese families.

Chapter 4: Integration of Quantitative and Qualitative Phases

This dissertation used a sequential mixed-methods design, with the integration of QUAN and qual occurring both at the methods stage and at the interpretation and reporting stage. This final chapter provides an overarching discussion integrating the results from Phase 1 and Phase 2 and presents the policy and clinical implications of these findings. Next, the strengths and limitations of this study are discussed, followed by the conclusion of this study.

Integrated Discussion

The purpose of this mixed-methods study was to explore the implementation gap in ABA-based services for children with autism in Taiwan. In phase 1, 147 parents of children with autism completed a survey assessing their knowledge, attitudes, and practices related to autism and ABA-based treatment. In phase 2, 10 parent participants from phase 1 and five ABA-based service professionals participated in semi-structured interviews. In the quantitative phase of the study, knowledge of ABA was the sole significant predictor of ABA-based service use, over and above child characteristics and other parent variables (i.e., knowledge of autism and attitudes about ABA). Several modifiable barriers to ABA-based services that contributed to this knowledge gap were identified at the level of the adopter (i.e., lack of training resources for parents, lack of timely information about ABA), of the innovation (i.e., lack of clarity of communication about ABA methodology), and of the environment (i.e., lack of clear guidelines for ABA-based services). Implications and suggestions for policymakers as well as clinical relevance for parents, teachers, ABA-based service providers, and healthcare professionals working with children with autism and their families are discussed below.

Improving Access to Information Sources and Providing Parent Training

The key finding from this study was that parents with an awareness and understanding of ABA were more likely to choose ABA-based services. In phase 1, many of the parents who did not use ABA were not aware of ABA-based services as a type of autism intervention. Therefore, the first step for increasing ABA-based service use will be to raise awareness. As identified in phase 2, increasing the accessibility of ABA information by providing information in Chinese that is also relevant to the Taiwan community, through online forums and workshops, may help to increase awareness amongst parents, and more broadly, i.e., teachers, healthcare providers, and policy makers.

Many parents who were aware of ABA-based services were motivated to gain a deeper understanding about ABA methodology, however, they were limited by the lack of parent training courses available. Parents who were able to obtain parent training reported feeling more confident about their parenting strategies, a finding that is consistent with existing studies elsewhere (Dillenburger et al., 2002, 2004). Current research also suggests that providing behavioural training to parents leads to lasting benefits for the child, parents, and the family (Dillenburger et al., 2004; Feldman & Werner, 2002). In the study by Feldman and Werner (2002), training was provided to parents of children with a developmental disability for 1 to 2 hours weekly for 3 to 6 months. For up to five years after the completion of the training, parents reported significantly less child behaviour difficulties as well as greater child and family quality of life compared to parents who did not receive the training. These results suggest that, although great effort is needed to build up programs that train parents in understanding and implementing ABA principles, this training will likely have lasting benefits for both the child and family.

In addition to increasing awareness about ABA-based services, clarifying and deepening parent understanding about ABA methodology is an important step in addressing the ABA-based implementation gap. Along with in-person classroom training models, it may be helpful to produce online short videos that can be easily shared online and viewed in order to reach a wider audience. Given that many parents in this study found out about the study through parent online groups, it would be important to connect future parents to these groups where accurate ABA information can be shared. Furthermore, it may also be useful to provide training courses to extended family members (e.g., grandparents, aunts, uncles) and nannies as they often play a large role in the child's day-to-day life. By including extended family members and nannies, this could help behavioural strategies to be implemented consistently (especially in the case of challenging behaviour approaches), help with the adherence to the intervention and, more importantly, lead to improvements in the child.

Educating Teachers and Healthcare Professionals

The results of this study also highlight a need to educate teachers, physicians, and other professionals involved in the child's care. In both phase 1 and phase 2, teachers and healthcare professionals were considered to be trusted sources of information in learning about types of autism treatments. Especially within Taiwan, where the diagnosis of autism is given by medical doctors, there is a critical need for these professionals to know enough about the literature on ABA-based services to guide families in choosing appropriate evidence-based interventions. Findings from phase 2 also suggest that the education system was often a barrier for ABA-based services and that misunderstandings often occurred, with many teachers not understanding ABA methodology or the role of the ABA-based service provider. This finding is particularly interesting given that in order to become a special education teacher in Taiwan, teachers are

required to undergo training on basic ABA principles. This finding is also consistent with previous studies in Taiwan which found that, even amongst special education teachers in elementary schools, only one third demonstrated a high level of knowledge and a high level of ABA usage (Zheng et al., 2018). Since teachers are a common and often valuable source of information for parents, increasing teacher knowledge may help with providing parents with timely information about ABA. Future studies should also examine why this knowledge in ABA still remains limited amongst teachers who have received prior ABA training.

Improving Communication of ABA Terms and Methodology

The findings from this dissertation also indicate that ABA terminology and methodology were difficult for parents in this sample to understand. This was reflected in the low ABA knowledge scores in phase 1 and also echoed in the qualitative findings from phase 2. These results are consistent with findings from previous research which suggests that ABA's technical terminology frequently elicits negative emotions from the general public (Critchfield et al., 2017; Critchfield & Doepke, 2018; Rolider et al., 1998). Critchfield and colleagues (2017; 2018) provided various behaviour analysis terms (e.g., discrimination, escape, extinction, punishment) in six languages (i.e., English, Egyptian Arabic, French, German, Brazilian Portuguese, and Spanish) to be rated by members of the general public. It was found that the negative perception of these commonly used terms in ABA occurred across these languages. Although the studies did not examine the Chinese language, it is likely that the negative perception towards ABA terminology also exists in the translated Chinese terms.

In response to this, ABA-based service professionals need to be proficient in both technical and non-technical communication and be able to tailor their communication style depending on the needs of the audience (Kelly et al., 2019). The main focus should be on

providing real-life examples and strategies that incorporate ABA methodology (Rolider et al., 1998). Furthermore, specific strategies often seen in ABA-based intervention sessions should also be explained to parents in a relatable manner. To the uninformed observer, watching a good ABA-based service provider in a one-to-one setting with a young child may look no different than a play session. However, there are often many elements that are being used within the sessions, such as the use of praise and other reinforcers to keep the child motivated, together with specific measurable goals and data-based decision-making.

Clear communication with parents is particularly important as ABA-based services in Taiwan are currently operating under a business model. Parents understandably want to see improvements, and usually within a short time frame, as the cost is quite high. However, what improvement looks like and how long it takes for it to occur, is unique to each individual child. As a result, it is imperative for ABA-based service providers to communicate this to parents early on and manage parents' expectations. Furthermore, it could be helpful for ABA-based service providers to operationally define what these improvements look like and to show parents ABA graphs so that parents can see the data themselves. Parents could also be encouraged to graph their own data if they are using ABA strategies at home. If costs allow, the addition of observational rooms or the possibility of having video-recordings in 1:1 sessions could be explored as long as privacy concerns are also addressed. This could help with “demystifying” what occurs during ABA-based sessions by allowing parents to see the sessions without distracting the child or therapist. For home-based ABA sessions, ABA-based therapists could also involve the parents during the sessions in order for parents to observe and learn strategies.

Developing a clear guideline for ABA-based services

The tensions, expressed by both parents and ABA-based service providers, with the fee-for-service delivery model of ABA-based services, were highlighted in both phases of the study. In addition, the lack of local certification contributed to the variable quality in services and also further contributed to misconceptions about ABA, leading parents and professionals to feel frustrated. Unfortunately, these experiences are not unique to Taiwan, and similar challenges are faced in European regions where behaviour analysis is also not recognized as a profession (Kelly et al., 2019). Taiwan, however, faces an additional barrier given its proximity to Mainland China where, just across the border, there is the lure of better pay and professional recognition. As a result, this contributes to a further decrease of ABA-based services in Taiwan as many service providers leave to Mainland China. Given this, there is a critical need in Taiwan to retain the limited number of professionals who do practice ABA-based services.

Examining the history and adoption of ABA-based services, it is clear that parents have been a critical driving force in the dissemination of ABA internationally (Kelly et al., 2019). In the U.S., ABA-based services were first endorsed by the Surgeon General (1999), and due to pressure from parent advocacy groups, professionals and organizations, all 50 states now require insurance companies to cover ABA-based services (Autism Speaks, 2019). In the province of Ontario, Canada, ABA-based services have gone through a similar developmental process over the past 30 years of ABA-based service adoption, and most other Canadian provinces now offer some level of ABA-based services. Furthermore, there has been a recent movement to have ABA-service providers regulated within the College of Psychologists of Ontario (2019).

Despite the obvious differences in healthcare systems and cultures, barriers to ABA-based implementation identified in Taiwan are also similar to challenges currently faced in other

countries. Similar to Taiwan, there is no legislation or government funded ABA-based services available in Ireland (Dillenburger et al., 2010). As a result, ABA-based intervention also faces many of the same challenges such as inconsistent quality (Dillenburger et al., 2012) and the lack of knowledge about ABA of special needs teachers (Fennell & Dillenburger, 2018). In Germany, ABA is also not recognized as a healthcare profession and there are no courses leading to a degree in ABA (Keenan et al., 2015). Historically, the U.S. and Canada also faced similar challenges to implementation. Therefore, looking at regions where ABA-based services are further along in the developmental process may be helpful for Taiwan in addressing similar barriers. For instance, the Association for Behaviour Analysis International (Autism Special Interest Group (SIG), 2018) has created parent guidelines (accessible in English only) to help parents navigate the process of selecting ABA-based service. A similar guideline with input from local stakeholders, with specific attention to the needs relevant to Taiwan, could be developed as a promising first step in helping parents and other service providers navigate ABA-based services and could provide more recognition to the field. Through this bottom-up approach, a laudable end goal would be to develop a national guideline endorsed by the Taiwan government.

Strengths and Limitations

This is the largest known study that has examined how parents in Taiwan perceive autism and ABA-based treatments and how these factors affect the selection of ABA-based intervention. Using a mixed-methods design, this study capitalized on the strengths of both qualitative and quantitative methodologies and examined first-person accounts of parents and ABA-based service providers in Taiwan. However, the findings from this study must be considered in light of its limitations. First, despite the relatively large sample size, parents were recruited from various community agencies, autism centers and through convenience sampling, and the majority

of these parents were highly educated. Throughout the three months of data collection, several efforts were made to increase the representativeness of the sample by contacting professionals working in the field of autism and by posting in online parent groups. Although their experiences may not be representative of all parents in Taiwan, the finding that knowledge of ABA remains a barrier even for a highly educated sample further underscores the importance of informing parents about evidence-based treatment options. In order to fully understand the experience of Taiwanese parents, however, future studies should strive to include parents from more diverse backgrounds.

Related to this, the parent participants for phase 2 were directly recruited based on their participation in phase 1. Although many of the parents expressed interest in participation, only 10 parents were able to be interviewed. Therefore, potential differences may exist for parents who did not express interest in participating, or those who expressed interest but declined to schedule an interview. For these reasons, it cannot be assumed that this sample is representative of all parents who have selected ABA-based services in Taiwan.

Another limitation to this study was the small number of ABA-based service users, only 8% of the sample, which was not ideal from a research standpoint, but was likely an accurate reflection of the status of ABA-based services in Taiwan. The small sample size limited the types of quantitative analyses that could be done and the conclusions that could be drawn from phase 1. For instance, the decision was made to combine both parents who were currently using and those who have previously used ABA-based services into one group in order to examine predictive factors. Future studies on the selection of ABA-based services should focus on examining the relationship between treatment selection factors with various characteristics of ABA-based service use, such as the current status of usage (i.e., currently using or stopped

using), differences in frequency and duration of sessions, and different formats of instruction (i.e., individual or group, home-based or centre-based). The small sample size also meant that only seven variables could be chosen as independent predictor variables since a binomial logistic regression depends on maximum likelihood estimation. For future research, it would be imperative to examine the role of additional child and parent variables in predicting ABA-based service use using a larger sample size and whether knowledge of ABA remains a significant predictor.

Another limitation to this study is related to autism diagnostic validity and severity. Although participants for the quantitative and qualitative phase were required to have received an autism diagnosis from a healthcare professional for their child, this was based on self-report and the diagnosis was not confirmed for this study. In order to address this limitation, however, participants were asked to complete the SCQ, which is a validated measure used to screen for autism symptoms. Since the autism diagnosis can only be given by medical doctors in Taiwan and the mean age of the children in the sample was 8, a parent-reported diagnosis of autism with a lower cut-off score of 11 was used as the inclusion criteria the findings from Corsello et al. (2007) suggest that this could increase the sensitivity of this measure for children who are 8 year-old or younger. The lower SCQ scores may also reflect milder symptoms of autism in this sample, and therefore, these findings may not be representative of parents of children with more severe autism symptoms.

Although one of the strengths of this study was the inclusion of an adaptive measure (i.e., the G04KIDDS Adaptive Behaviour scale) which has been validated in a Canadian sample, the measure has not been previously used in a Taiwan sample. The decision was made to include a brief measure of adaptive behaviour (i.e., 8 items), rather than other traditionally used and well-

developed measures such as the Vineland Adaptive Behaviour Scales (Sparrow et al., 2005) due to constraints in the length of the questionnaire. Despite research indicating a high convergent validity ($r=.81$) with the teacher version of the Vineland Adaptive Behavior Scale (Pan et al., 2019), results should be viewed in light of this limitation and future studies should examine the appropriateness of the GO4KIDDS measure for use in Taiwan.

Due to the limited studies on autism service utilization in Taiwan, phase 1 of the study was largely exploratory and included measures that were previously developed for a Canadian population but were not validated for a Taiwanese sample. Although the questions were adapted with the input of a local expert and pilot-tested with three parents, the measures were potentially limited. For example, the coefficient alpha for the autism knowledge scale was lower in the Taiwan population than for the Canadian population (although ABA knowledge and ABA attitudes had acceptable alphas). The lower alpha obtained in this current study could be due to the fact that the knowledge of autism and ABA was used separately, rather than as a combined measure in the original Solish & Perry (2008) study. Furthermore, differences may be due to sample sizes (i.e., 149 Taiwan participants compared to 48 Canadian participants) or cultural appropriateness as the original study was validated in a Canadian population. Results should be interpreted with this in mind. Although this study adds to the growing literature on what parents know about ABA and autism, future research is needed to independently validate these measures, or other more culturally appropriate ones, for use in Taiwan.

References

- Al Anbar, N. N., Dardennes, R. M., Prado-Netto, A., Kaye, K., & Contejean, Y. (2010). Treatment choices in autism spectrum disorder: The role of parental illness perceptions. *Research in Developmental Disabilities, 31*(3), 817–828.
<https://doi.org/10.1016/j.ridd.2010.02.007>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Autism Society Canada. (2018). *Behavioural Intervention*. <https://autismcanada.org/living-with-autism/treatments/non-medical/>
- Autism Speaks. (2019). *Autism Speaks commends Tennessee as it becomes 50th state requiring that insurance plans cover autism*. <https://www.autismspeaks.org/press-release/autism-speaks-commends-tennessee-it-becomes-50th-state-requiring-insurance-plans>
- Autism Special Interest Group (SIG). (2018). *Parent Guidelines for Identifying, Selecting, and Evaluating Behavior Analysts Providing Treatment for Individuals Diagnosed with Autism Spectrum Disorder*.
- BACB. (2020a). *Global Certification*. Retrieved November 15th, 2020 from <https://www.bacb.com/global-certification/>
- BACB. (2020b). *BACB Certificant Registry*. Retrieved November 15th, 2020 from <https://www.bacb.com/services/o.php?page=101135&s=1>
- Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91-97.
<https://doi.org/10.1901/jaba.1968.1-91>

- Bailey, J. S. (1991). Marketing behavior analysis requires different talk. *Journal of Applied Behavior Analysis*, 24(3), 445–448. <https://doi.org/10.1901/jaba.1991.24-445>
- Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 45(3), 601–613. <https://doi.org/10.1017/S003329171400172X>
- Birks, M., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, 13(1), 68-75. <https://doi.org/10.1177/1744987107081254>
- Bölte, S., Girdler, S., & Marschik, P. B. (2019). The contribution of environmental exposure to the etiology of autism spectrum disorder. *Cellular and Molecular Life Sciences*, 76(7), 1275–1297. <https://doi.org/10.1007/s00018-018-2988-4>
- Bowker, A., D'Angelo, N. M., Hicks, R., & Wells, K. (2011). Treatments for autism: Parental choices and perceptions of change. *Journal of Autism and Developmental Disorders*, 41(10), 1373–1382. <https://doi.org/10.1007/s10803-010-1164-y>
- Bruininks, R. H., Woodcock, R. W., Weatherman, R. F., & Hill, B. K. (1996). *Scales of Independent Behavior—Revised Comprehensive Manual*. Itasca, IL: Riverside Publishing.
- Carlson, S., Carter, M., & Stephenson, J. (2013). A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions. *Research in Autism Spectrum Disorders*, 7(2), 369–381. <https://doi.org/10.1016/j.rasd.2012.10.009>
- Chaidez, V., Fernandez y Garcia, E., Wang, L. W., Angkustsiri, K., Krakowiak, P., Hertz-Picciotto, I., & Hansen, R. L. (2018). Comparison of maternal beliefs about causes of

autism spectrum disorder and association with utilization of services and treatments.

Child: Care, Health and Development, 44(6), 916–925.

<https://doi.org/10.1111/cch.12612>

Chang, K. (2017). Applied behavior analysis in autism spectrum disorders in China and Hong Kong. *Acta Psychopathologica*, 3:52. <https://doi.org/10.4172/2469-6676.100124>

Chen, L. S., Li, C., Wang, C. H., Amuta, A., Li, M., Huang, T. Y., Dhar, S. U., Talwar, D., & Jung, E. (2015). Autism spectrum disorders: perceptions of genetic etiology and recurrence risk among Taiwanese parents of affected children. *Clinical Genetics*, 88(2), 129–134. <https://doi.org/10.1111/cge.12514>

Chen, L., Xu, L., Huang, T. Y., & Dhar, S. U. (2013). Autism genetic testing: A qualitative study of awareness, attitudes, and experiences among parents of children with autism spectrum disorders. *Genetics in Medicine*, 15, 274–281. <https://doi.org/10.1038/gim.2012.145>

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. *Journal of Developmental and Behavioral Pediatrics*, 27(2), 145–155. <https://doi.org/10.1097/00004703-200604002-00013>

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd ed.). Upper Saddle River, NJ: Pearson Education, Inc.

Corsello, C., Hus, V., Pickles, A., Risi, S., Cook, E. H., Leventhal, B. L., & Lord, C. (2007). Between a ROC and a hard place: Decision making and making decisions about using the SCQ. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 48(9), 932–940. <https://doi.org/10.1111/j.1469-7610.2007.01762.x>

- Creswell, J. W., Iano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook on mixed methods in the behavioral and social sciences* (pp. 209–240). Sage Publications.
- Critchfield, T. S., & Doepke, K. J. (2018). Emotional overtones of behavior analysis terms in English and five other languages. *Behavior Analysis in Practice, 11*(2), 97–105.
<https://doi.org/10.1007/s40617-018-0222-3>
- Critchfield, T. S., Doepke, K. J., Kimberly Epting, L., Becirevic, A., Reed, D. D., Fienup, D. M., Kreamsreiter, J. L., & Ecott, C. L. (2017). Normative emotional responses to behavior analysis jargon or how not to use words to win friends and influence people. *Behavior Analysis in Practice, 10*(2), 97–106. <https://doi.org/10.1007/s40617-016-0161-9>
- Daley, T. C. (2002). The need for cross-cultural research on the pervasive developmental disorders. *Transcultural Psychiatry, 39*(4), 531–550.
<https://doi.org/10.1177/136346150203900409>
- Dardennes, R. M., Al Anbar, N. N. N., Prado-Netto, A., Kaye, K., Contejean, Y., & Al Anbar, N. N. (2011). Treating the cause of illness rather than the symptoms: Parental causal beliefs and treatment choices in autism spectrum disorder. *Research in Developmental Disabilities, 32*(3), 1137–1146. <https://doi.org/10.1016/j.ridd.2011.01.010>
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7). <https://doi.org/10.1007/s10803-007-0512-z>
- Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Living with children diagnosed with autistic spectrum disorder: parental and professional views.

British Journal of Special Education, 37(1). <https://doi.org/10.1111/j.1467-8578.2010.00455.x>

- Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2012). ABA-based programs for children diagnosed with autism spectrum disorder: Parental and professional experiences at school and at home. *Child and Family Behavior Therapy*, 34(2), 111–129. <https://doi.org/10.1080/07317107.2012.684645>
- Dillenburger, K., Keenan, M., Gallagher, S., & McElhinney, M. (2002). Autism: Intervention and parental empowerment. *Child Care in Practice*, 8(3), 216–219. <https://doi.org/10.1080/1357527022000040426>
- Dillenburger, K., Keenan, M., Gallagher, S., & McElhinney, M. (2004). Parent education and home-based behaviour analytic intervention: An examination of parents' perceptions of outcome. *Journal of Intellectual and Developmental Disability*, 29(2), 119–130. <https://doi.org/http://dx.doi.org/10.1080/13668250410001709476>
- Dingfelder, H. E., & Mandell, D. S. (2011). Bridging the research-to-practice gap in autism intervention: An application of diffusion of innovation theory. *Journal of Autism and Developmental Disorders*, 41(5), 597–609. <https://doi.org/10.1007/s10803-010-1081-0>
- Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism: A 1-year comparison controlled study. *Behavior Modification*, 26(1), 49–68. <https://doi.org/10.1177/0145445502026001004>
- Eldevik, S., Hastings, R. P., Jahr, E., & Hughes, J. C. (2012). Outcomes of behavioral intervention for children with autism in mainstream pre-school settings. *Journal of Autism and Developmental Disorders*, 42(2), 210–220. <https://doi.org/10.1007/s10803-011-1234-9>

- Feldman, M. A., & Werner, S. E. (2002). Collateral effects of behavioral parent training on families of children with developmental disabilities and behavior disorders. *Behavioral Interventions*, 17(2). <https://doi.org/10.1002/bin.111>
- Fennell, B., & Dillenburger, K. (2018). Applied behaviour analysis: What do teachers of students with autism spectrum disorder know. *International Journal of Educational Research*, 87, 110–118. <https://doi.org/10.1016/j.ijer.2016.06.012>
- Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving integration in mixed methods designs - Principles and practices. *Health Services Research*, 48(6 PART2), 2134–2156. <https://doi.org/10.1111/1475-6773.12117>
- Freedman, D. H. (2016). Improving public perception of behavior analysis. *Behavior Analyst*, 39(1), 89–95. <https://doi.org/10.1007/s40614-015-0045-2>
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1), 117. <https://doi.org/10.1186/1471-2288-13-117>
- Gau, S. S. F., Lee, C. M., Lai, M. C., Chiu, Y. N., Huang, Y. F., Kao, J. Der, & Wu, Y. Y. (2011). Psychometric properties of the Chinese version of the Social Communication Questionnaire. *Research in Autism Spectrum Disorders*, 5(2), 809–818. <https://doi.org/10.1016/j.rasd.2010.09.010>
- Goin-Kochel, R. P., & Myers, B. J. (2005). Congenital versus regressive onset of autism spectrum disorders: Parents' beliefs about causes. *Focus on Autism and Other Developmental Disabilities*, 20(3), 169–179. <https://doi.org/10.1177/10883576050200030501>

- Goin-Kochel, R. P., Myers, B. J., Hendricks, D. R., Carr, S. E., & Wiley, S. B. (2007). Early responsiveness to intensive behavioural intervention predicts outcomes among preschool children with Autism. *International Journal of Disability, Development and Education*, 54(2), 151–175. <https://doi.org/10.1080/10349120701330404>
- Granpeesheh, D., Kenzer, A., & Tarbox, J. (2011). Comparison of two-year outcomes for children with autism receiving high versus low-intensity behavioral intervention. *European Psychiatry*, 26(S2), 1839–1839. [https://doi.org/10.1016/s0924-9338\(11\)73543-x](https://doi.org/10.1016/s0924-9338(11)73543-x)
- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27(1), 70–84. <https://doi.org/10.1016/j.ridd.2004.12.002>
- Harris, S. L., & Handleman, J. S. (2000). Age and IQ at intake as predictors of placement for young children with autism: a four- to six-year follow-up. *Journal of Autism and Developmental Disorders*, 30(2), 137–142. <https://doi.org/10.1023/A:1005459606120>
- Hartley, S. L., Sikora, D. M., & McCoy, R. (2008). Prevalence and risk factors of maladaptive behaviour in young children with autistic disorder. *Journal of Intellectual Disability Research*, 52 (10), 819-829. <https://doi.org/10.1111/j.1365-2788.2008.01065.x>
- Henderson, J. L., MacKay, S., & Peterson-Badali, M. (2006). Closing the research-practice gap: Factors affecting adoption and implementation of a children's mental health program. *Journal of Clinical Child and Adolescent Psychology*, 35(1). https://doi.org/10.1207/s15374424jccp3501_1

- Henshaw, E. J., & Freedman-Doan, C. R. (2009). Conceptualizing mental health care utilization using the health belief model. *Clinical Psychology: Science and Practice, 16*, 420–439. <https://doi.org/10.1111/j.1468-2850.2009.01181.x>
- Hill, A. P., Zuckerman, K. E., Hagen, A. D., Kriz, D. J., Duvall, S. W., Van Santen, J., Nigg, J., Fair, D., & Fombonne, E. (2014). Aggressive behavior problems in children with autism spectrum disorders: Prevalence and correlates in a large clinical sample. *Research in Autism Spectrum Disorders, 8*(9), 1121–1133. <https://doi.org/10.1016/j.rasd.2014.05.006>
- Hochbaum, G. M. (1958). *Public participation in medical screening programs: A sociopsychological study*. U.S Government Printing Office.
- Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities, 26*(4), 359–383. <https://doi.org/10.1016/j.ridd.2004.09.005>
- Howard, J. S., Stanislaw, H., Green, G., Sparkman, C. R., & Cohen, H. G. (2014). Comparison of behavior analytic and eclectic early interventions for young children with autism after three years. *Research in Developmental Disabilities, 35*(12), 3326–3344. <https://doi.org/https://dx.doi.org/10.1016/j.ridd.2014.08.021>
- Hsu, Y.-C., Tsai, S.-L., Hsieh, M.-H., Jenks, M. S., Tsai, C.-H., & Hsu, M.-T. (2017). On my own: A qualitative phenomenological study of mothers of young children with autism spectrum disorder in Taiwan. *Journal of Applied Research in Intellectual Disabilities, 30*(1), 147–156. <https://doi.org/10.1111/jar.12229>

- Ivankova, N. V., Creswell, J. W., & Stick, S. L. (2006). Using mixed-methods sequential explanatory design: From theory to practice. *Field Methods*, 18(1), 3–20.
<https://doi.org/10.1177/1525822X05282260>
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112–133.
<https://doi.org/10.1177/1558689806298224>
- Kang, Y., Lovett, D., & Haring, K. (2002). Culture and special education in Taiwan. *Teaching Exceptional Children*, 34(5), 12–15. <https://doi.org/10.1177/004005990203400502>
- Kanne, S. M., & Mazurek, M. O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders*, 41, 926–937. <https://doi.org/10.1007/s10803-010-1118-4>
- Kanne, S. M., Mazurek, M. O., Sikora, D., Bellando, J., Branum-Martin, L., Handen, B., Katz, T., Freedman, B., Powell, M. P., & Warren, Z. (2014). The autism impact measure (AIM): Initial development of a new tool for treatment outcome measurement. *Journal of Autism and Developmental Disorders*, 44, 168–179. <https://doi.org/10.1007/s10803-013-1862-3>
- Keenan, M., Dillenburger, K., Moderato, P., & Röttgers, H.-R. (2010). Science for sale in a free market economy: But at what price? ABA and the treatment of autism in Europe. *Behavior and Social Issues*, 19(1), 126–143. <https://doi.org/10.5210/bsi.v19i0.2879>
- Keenan, M., Dillenburger, K., Röttgers, H. R., Dounavi, K., Jónsdóttir, S. L., Moderato, P., Schenk, J. J. A. M., Virués-Ortega, J., Roll-Pettersson, L., & Martin, N. (2015). Autism and ABA: The gulf between North America and Europe. *Review Journal of Autism and Developmental Disorders*, 2(2), 167–183. <https://doi.org/10.1007/s40489-014-0045-2>

- Kelly, M. P., Martin, N., Dillenburger, K., Kelly, A. N., & Miller, M. M. (2019). Spreading the news: History, Successes, challenges and the ethics of effective dissemination. *Behavior Analysis in Practice*, 12(2), 440–451. <https://doi.org/10.1007/s40617-018-0238-8>
- Kenny, L., Hattersley, C., Mollins, B., Buckley, C., Povey, & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.
- Koch, T. (1994). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, 19, 976–986. <https://doi.org/10.1111/j.1365-2648.1994.tb01177.x>
- Levy, S. E., & Hyman, S. L. (2008). Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America*, 17(4), 803–820. <https://doi.org/10.1016/j.chc.2008.06.004>
- Liao, Y., Dillenburger, K., & Buchanan, I. (2018). Does culture matter in ABA-based autism interventions? Parent and professional experiences in the UK and China. *European Journal of Behavior Analysis*, 19(1), 11–29.
<https://doi.org/10.1080/15021149.2017.1399657>
- Liao, Y., Dillenburger, K., He, W., Xu, Y., & Cai, H. (2020). A Systematic review of applied behavior analytic interventions for children with autism in mainland China. *Review Journal of Autism and Developmental Disorders*, 1–19. <https://doi.org/10.1007/s40489-020-00196-w>
- Lin, L. Y. (2014). Stressors, cultural values and maternal well-being in Taiwanese mothers of individuals with autism spectrum disorder. *Asia Pacific Journal of Counselling and Psychotherapy*, 5(2), 157–171. <https://doi.org/10.1080/21507686.2014.913642>

Lin, T., Chiang, C., Ho, S. Y., Wu, H. C., & Wong, C. C. (2020). Preliminary clinical outcomes of a short-term low-intensity Early Start Denver Model implemented in the Taiwanese public health system. *Autism*. Advance online publication.

<https://doi.org/10.1177/1362361319897179>

Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3–9.

<https://doi.org/10.1037/0022-006x.55.1.3>

Luiselli, J. K., Cannon, B. O., Ellis, J. T., & Sisson, R. W. (2000). Home-based behavioral intervention for young children with autism/pervasive developmental disorder: A preliminary evaluation of outcome in relation to child age and intensity of service delivery. *Autism*, 4(4), 426–438. <https://doi.org/10.1177/1362361300004004007>

Mccabe, H. (2012). Bamboo shoots after the rain: Development and challenges of autism intervention in China. *Autism*, 17(5), 510–526.

<https://doi.org/10.1177/1362361312436849>

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, 97(4), 359–372.

Mercer, L., Creighton, S., Holden, J. J. A., & Lewis, M. E. S. (2006). Parental perspectives on the causes of an autism spectrum disorder in their children. *Journal of Genetic Counseling*, 15, 41–50. <https://doi.org/10.1007/s10897-005-9002-7>

- Miller, V. A., Schreck, K. A., Mulick, J. A., & Butter, E. (2012). Factors related to parents' choices of treatments for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), 87–95. <https://doi.org/10.1016/j.rasd.2011.03.008>
- Ministry of Education (1979). Special Education School Teachers Registration Regulations-No. 5603 Amendment.
- Mire, S. S., Gealy, W., Kubiszyn, T., Burridge, A. B., & Goin-Kochel, R. P. (2017). Parent perceptions about autism spectrum disorder influence treatment choices. *Focus on Autism and Other Developmental Disabilities*, 32(4), 305–318. <https://doi.org/10.1177/1088357615610547>
- Morse, J. M. (2008). “What’s your favorite color?” Reporting irrelevant demographics in qualitative research. *Qualitative Health Research*, 18(3), 299–300. <https://doi.org/10.1177/1049732307310995>
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2). <https://doi.org/10.1177/160940690200100202>
- Morse, J. M., & Coulehan, J. (2015). Maintaining confidentiality in qualitative publications. *Qualitative Health Research*, 25(2), 151–152. <https://doi.org/10.1177/1049732314563489>
- National Autism Center. (2009). *The National Autism Center’s the national standards project-addressing the need for evidence-based practice guidelines for autism spectrum disorders National Standards Report*. NAC, Randolph.
- National Autism Center. (2015). *National Standards Project, Phase 2 addressing the need for evidence-based practice guidelines for autism spectrum disorder*. NAC, Randolph.

- Nicol, G. E., Morrato, E. H., Johnson, M. C., Campagna, E., Yingling, M. D., Pham, V., & Newcomer, J. W. (2011). Best practices: Implementation of a glucose screening program based on diffusion of innovation theory methods. *Psychiatric Services*, 62(1), 12-14. <https://doi.org/10.1176/appi.ps.62.1.12>
- O'Connor, B. B., Calabrese, C., Cardena, E., Eisenberg, D., Fincher, J., Hufford, D. J., Jonas, W. B., Kaptchuk, T., Martin, S. C., Scott, A. W., & Zhang, X. (1997). Defining and describing complementary and alternative medicine. *Alternative Therapies in Health and Medicine*, 3(2), 49–57. <https://experts.umn.edu/en/publications/defining-and-describing-complementary-and-alternative-medicine>
- Odom, S. L., Collet-Klingenberg, L., Rogers, S. J., & Hatton, D. D. (2010). Evidence-based practices in interventions for children and youth with autism spectrum disorders. *Preventing School Failure: Alternative Education for Children and Youth*, 54(4), 275–282. <https://doi.org/10.1080/10459881003785506>
- Odom, S. L., Hall, L. J., & Suhrheinrich, J. (2019). Implementation science, behavior analysis, and supporting evidence-based practices for individuals with autism. *European Journal of Behavior Analysis*, 21(1), 55-73. <https://doi.org/10.1080/15021149.2019.1641952>
- Owen-Smith, A. A., Bent, S., Lynch, F. L., Coleman, K. J., Yau, V. M., Pearson, K. A., Massolo, M. L., Quinn, V., & Croen, L. A. (2015). Prevalence and predictors of complementary and alternative medicine use in a large insured sample of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 17, 40–51. <https://doi.org/10.1016/j.rasd.2015.05.002>
- Pan, X., Totsika, V., Nicholls, G., & Paris, A. (2019). Validating GO4KIDDS as a brief measure of adaptive skills in special education settings for children with severe intellectual

- disability. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 280-287.
<https://doi.org/10.1111/jar.12524>
- Perry, A., Blacklock, K., & Dunn Geier, J. (2013). The relative importance of age and IQ as predictors of outcomes in Intensive Behavioral Intervention. *Research in Autism Spectrum Disorders*, 7(9), 1142–1150. <https://doi.org/10.1016/j.rasd.2013.06.004>
- Perry, A., Koudys, J., & Blacklock, K. (2016). Early intensive behavioural intervention and training. In N.N. Singh (Ed.), *Clinical Handbook of Evidence-based Practices for Individuals with Intellectual Disabilities*. Springer. DOI: 10.1007/978-3-319-26583-4
- Perry, A., Koudys, J., Prichard, A., & Ho, H. (2017). Follow-up study of youth who received eibi as young children. *Behavior Modification*, 43(2), 145445517746916.
<https://doi.org/10.1177/0145445517746916>
- Perry, A., Taheri, A., Ting, V., & Weiss, J. (2015). The GO4KIDDS Brief Adaptive Scale. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 594–597.
<https://doi.org/10.1111/jar.12143>
- Pickard, K. E., Kilgore, A. N., & Ingersoll, B. R. (2016). Using community partnerships to better understand the barriers to using an evidence-based, parent-mediated intervention for autism spectrum disorder in a medicaid system. *American Journal of Community Psychology*, 57(3–4), 391–403. <https://doi.org/10.1002/ajcp.12050>
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21(2), 311–319. <https://doi.org/10.1007/s10826-011-9477-9>
- Remington, B., Hastings, R. P., Kovshoff, H., Espinosa, F. D., Jahr, E., Brown, T., Alsford, P., Lemaic, M., & Ward, N. (2007). Early intensive behavioral intervention: Outcomes for

- children with autism and their parents after two years. *American Journal on Mental Retardation*, 112(6), 418–438. [https://doi.org/10.1352/0895-8017\(2007\)112\[418:EIBIOF\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2007)112[418:EIBIOF]2.0.CO;2)
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (Eds.), *Analyzing qualitative data*. Routledge. https://doi.org/10.4324/9780203413081_chapter_9
- Ritchie, J., Spencer, L., & O'Connor, W. (2003). Carrying out Qualitative Analysis. In J. Ritchie & J. Lewis (Eds.), *Qualitative Research Practice: A guide for Social Science Students and Researchers*. Sage Publications. <https://doi.org/10.4135/9781452230108>
- Rogers, E. (2003). *The Diffusion of Innovations (Fifth Edition)*. Free Press.
- Rojahn, J., Rowe, E. W., Sharber, A. C., Hastings, R., Matson, J. L., Didden, R., Kroes, D. B. H., & Dumont, E. L. M. (2012). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part I: Development and provisional clinical reference data. *Journal of Intellectual Disability Research*, 56(5). <https://doi.org/10.1111/j.1365-2788.2011.01507.x>
- Rolider, A., Axelrod, S., & Van Houten, R. (1998). Don't speak behaviorism to me: How to clearly and effectively communicate behavioral interventions to the general public. *Child and Family Behavior Therapy*, 20(2), 39-56. https://doi.org/10.1300/J019v20n02_03
- Roll-Pettersson, L., Olsson, I., & Ala'i-Rosales, S. (2016). Bridging the research to practice gap: A case study approach to understanding EIBI supports and barriers in Swedish preschools. *International Electronic Journal of Elementary Education*, 9(2), 317–336.
- Rosentock, I. M. (1960). What research in motivation suggests for public health. *American Journal of Public Health*, 50, 295–301. https://doi.org/10.2105/ajph.50.3_pt_1.295

- Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation*, 110(6). [https://doi.org/10.1352/0895-8017\(2005\)110\[417:IBTFCW\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2005)110[417:IBTFCW]2.0.CO;2)
- Selkirk, C. G., McCarthy Veach, P., Lian, F., Schimmenti, L., & Leroy, B. S. (2009). Parents' perceptions of autism spectrum disorder etiology and recurrence risk and effects of their perceptions on family planning: Recommendations for genetic counselors. *Journal of Genetic Counseling*, 18, 507–519. <https://doi.org/10.1007/s10897-009-9233-0>
- Shepherd, D., Csako, R., Landon, J., Goedeke, S., & Ty, K. (2018). Documenting and understanding parent's intervention choices for their child with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(4). <https://doi.org/10.1007/s10803-017-3395-7>
- Shyu, Y.L., Tsai, J.L., & Tsai, W.C. (2010). Explaining and selecting treatments for autism: Parental explanatory models in Taiwan. *Journal of Autism and Developmental Disorders*, 40, 1323–1331. <https://doi.org/10.1007/s10803-010-0991-1>
- Smith, P. J., Humiston, S. G., Marcuse, E. K., Zhao, Z., Dorell, C. G., Howes, C., & Hibbs, B. (2011). Parental delay or refusal of vaccine doses, childhood vaccination coverage at 24 months of age, and the Health Belief Model. *Public Health Reports*, 126(2), 135–146. <https://doi.org/10.1177/00333549111260s215>
- Smith, T., Groen, A. D., Wynn, J. W., & Smith, T. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, 105(4), 269–285. [https://doi.org/10.1352/0895-8017\(2000\)105<0269:RTOIEI>2.0.CO;2](https://doi.org/10.1352/0895-8017(2000)105<0269:RTOIEI>2.0.CO;2)

- Solish, A., & Perry, A. (2008). Parents' involvement in their children's behavioral intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorders*, 2, 728–738. <https://doi.org/10.1016/j.rasd.2008.03.001>
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (2005). *Vineland-II adaptive behavior scales*. behavior scales. Circle Pines, MN: AGS.
- Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. S., Yücesoy-Özkan, S., and Savage, M. N. (2020) *Evidence-based practices for children, youth, and young adults with Autism*. The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team.
- Tabachnick, B. G., & Fidell, L. S. (2019). *Using Multivariate Statistics (7th edition)*. Pearson.
- Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Sage.
- The College of Psychologists of Ontario. (2019, September 27). *Meeting of the College Council*. <https://cpo.on.ca/wp-content/uploads/Materials-Council-Meeting-2019.03-September-27-2019.pdf>
- The Ontario Association for Behaviour Analysis (ONTABA). (2017). *Evidence-based practices for individuals with autism spectrum disorder: Recommendations of caregivers, practitioners, and policy makers*.
- Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, 29(1). <https://doi.org/10.1080/13668250410001662892>

Tzanakaki, P., Grindle, C., Hastings, R. P., Hughes, J. C., Kovshoff, H., & Remington, B.

(2012). How and why do parents choose early intensive behavioral intervention for their young child with autism? *Education and Training in Autism and Developmental Disabilities*, 47(1), 58–71.

U.S. Department of Health and Human Services. (1999). *Mental health: A report of the surgeon general*.

Wang, J., Hu, Y., Wang, Y., Qin, X., Xia, W., Sun, C., Wu, L., & Wang, J. (2013). Parenting stress in Chinese mothers of children with autism spectrum disorders. *Social Psychiatry and Psychiatric Epidemiology*, 48(4), 575–582. <https://doi.org/10.1007/s00127-012-0569-7>

Wang, J., Zhou, X., Xia, W., Sun, C. H., Wu, L. J., & Wang, J. L. (2012). Autism awareness and attitudes towards treatment in caregivers of children aged 3-6 years in Harbin, China. *Social Psychiatry and Psychiatric Epidemiology*, 47(8), 1301–1308. <https://doi.org/10.1007/s00127-011-0438-9>

Wejnert, B. (2002). Integrating models of diffusion of innovations: A conceptual framework. *Annual Review of Sociology*, 28, 297–326. <https://doi.org/10.1146/annurev.soc.28.110601.141051>

WHO. (2008). *Advocacy, communication and social mobilization for TB control. A guide to developing knowledge, attitude and practice surveys*.

Wilson, M., Hamilton, D., Whelan, T., & Pilkington, P. (2018). A systematic review of factors related to parents' treatment decisions for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 48, 17–35. <https://doi.org/10.1016/j.rasd.2018.01.004>

- Wolf, M., Risley, T., & Mees, H. (1963). Application of operant conditioning procedures to the behaviour problems of an autistic child. *Behaviour Research and Therapy*, 1, 305–312.
[https://doi.org/10.1016/0005-7967\(63\)90045-7](https://doi.org/10.1016/0005-7967(63)90045-7)
- Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., Brock, M. E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2015). Evidence-Based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, 45(7), 1951–1966.
<https://doi.org/10.1080/10459881003785506>
- Wong, V. (2009). Use of complementary and alternative medicine (CAM) in autism spectrum disorder (ASD): Comparison of Chinese and western culture (Part A). *Journal of Autism and Developmental Disorders*, 39(3). <https://doi.org/10.1007/s10803-008-0644-9>
- Wu, T. Y., Majeed, A., & Kuo, K. N. (2010). An overview of the healthcare system in Taiwan. *London Journal of Primary Care*, 2, 115–119.
<https://doi.org/10.1080/17571472.2010.11493315>
- Zheng, S., Chien, Y. K., Wang, H., & Feng, H. (2018). Current dissemination of applied behavior analysis in Taiwan: An example of the Taipei City elementary school special education teachers. *Bulletin of Special Education*, 43, 1–30.

Appendix A
Survey on Autism Spectrum Disorder Services in Taiwan (English)

This questionnaire has several different sections and is to be filled out by the parents or primary caregiver of the child who has been diagnosed with suspected autism or autism. The purpose of this study is to understand the types of services being used by parents & caregivers of children with autism in Taiwan.

Date questionnaire completed: _____

Section I: Family Background

The first section is included to help us understand the background of individuals who agree to participate in our study. In the case of a two parent family, one person can fill out the information for both partners.

1) What is your relationship to the child with ASD?

Biological Parent

Adoptive Parent

Step Parent

Grandparent

Guardian

Other (Please specify _____)

2) What is your gender?

Male

Female

Other (Please specify): _____

3) What is your marital status?

Married

Single Parent

Separated, divorced, or widowed

Other (Please specify): _____

4) Who lives in the household? (please check all apply)

Child's Biological Mother

Child's Biological Father

Child

Child's Sibling (s) (Please specify how many: _____)

Child's Grandparent (s) (Please specify how many: _____)

Nanny

Other (Please who and their relationship to child: _____)

4) What is the most frequent language spoken at home?

Mandarin Chinese

Taiwanese

Hakka

Aboriginal language (Please specify): _____

Other (Please specify): _____

5)

	Yourself	Partner
a) What is your/your partner's citizenship?	Taiwan Other (Please specify):	Taiwan Other (Please specify):
b) What is your/your partner's religion?	Taoist Buddhist Christian Catholic Islamic Not religious Other (Please specify)	Taoist Buddhist Christian Catholic Islamic Not religious Other (Please specify)
c) What is the highest level of education you/your partner has completed?	Elementary School Middle School High School College/University Masters or above	Elementary School Middle School High School College/University Masters or above
d) What is your/your partner's occupation?	Please specify occupation: _____ Employed full-time Employed part-time Not employed but seeking Not employed Stay at home parent Several part-time occupations	Please specify occupation: _____ Employed full-time Employed part-time Not employed but seeking Not employed Stay at home parent Several part-time occupations

6) How many children do you have? (If you are the guardian of the child, please answer how many children you are the primary caregiver for)

1

2

3

4 or more (please specify number: _____)

- 7) How many children diagnosed with autism/suspected of autism do you have?
- 1
 - 2
 - 3
 - 4 or more (please specify number: _____)

Section II: Child Background

In this section, we would like to know more about your child's background. If you have more than 1 child with ASD or suspected ASD, please fill out the following survey based on the first child you had diagnosed with ASD/suspected ASD

- 1) Is the child:
 - A boy
 - A girl
- 2) When was your child born? (MM/YY) _____
- 3) What type of diagnosis does your child have?
 - suspected autism
 - autism
- 4) If your child has a diagnosis of suspected autism or autism, please specify when they received the diagnosis (MM/YY): _____
- 5) Does your child have any of the following (*check all that apply*)
 - Problems using his/her legs (e.g., walking, running, standing – do not count clumsiness)
 - Problems using his/her hands (e.g., picking things up, holding a pencil)
 - Other problems with motor control/coordination (e.g., very clumsy)
 - Seizures
 - Major vision impairment
 - Major hearing impairment
 - Feeding or eating difficulties (gastro-intestinal problems, feeding tubes, major allergies and sensitivities, etc.)
 - Heart problems
 - Asthma or other respiratory disease
 - Physical dysmorphism (unusual looking face, head, eyes, ears, fingers, toes)
 - Other (please specify _____)

Child's Daily Functioning

The following questions are about your child's daily functioning abilities.

**Questions 6-14 are adapted from the GO4KIDDS Adaptive Behaviour scales (Perry et al., 2015)*

***Questions 15-17 are adapted from the Behavior Problems Inventory for Individuals with Intellectual Disabilities (Rojahn, 2011)*

6) What level of help or support is needed for your child (e.g. toileting, dressing, eating, etc.)?

- Requires support for almost all aspects of life
- Requires support for most, but not all, aspects of life
- Requires support for some aspects of life
- Requires support for only a few aspects of life
- Does not require support

7) How much does your child understand spoken language?

- Able to understand very little spoken language,
- Able to understand some basic language and simple instructions in familiar contexts (e.g. sit down)
- Able to understand most basic instructions and questions
- Able to understand most routine everyday language
- Able to understand complex language about a wide range of topics

8) How much does your child use spoken language to communicate?

- Able to use very little meaningful speech
- Able to communicate basic needs and wants
- Able to communicate needs, wants, and some ideas
- Able to communicate within a limited range of topics in a meaningful way
- Able to communicate about a wide variety of topics in a meaningful way

9) Does your child use Alternative & Augmentative Communication systems to communicate? (including sign language, PECS, voice output devices, etc.)

- No, does not use any alternative systems
- Yes, uses alternative augmentative communication (please specify: _____)

If yes, how well does your child communicate using this system?

- Able to use very little meaningful communication
- Able to communicate basic needs and wants
- Able to communicate needs, wants, and some ideas
- Able to communicate within a limited range of topics in a meaningful way
- Able to communicate about a wide variety of topics in a meaningful way

10) How much does your child engage in social interactions with familiar adults?

- Shows little or no interest in social interactions with familiar adults
- Shows limited social interest but will sometimes respond to familiar adults
- Shows some social interest, responds to others, but does not initiate social interactions with familiar adults
- Shows clear social interest, responds to others often and sometimes initiates social interactions with familiar adults
- Engages a wide range of social interactions involving both responding and initiating social contact with familiar adults

11) How much does your child engage in social interactions with other children?

- Shows little or no interest in social interactions with other children
- Shows limited social interest but will sometimes respond to other children
- Shows some social interest, responds to others, but does not initiate social interactions with other children
- Shows clear social interest, responds to others and sometimes initiates social interactions with other children
- Engages in a wide range of social interactions involving both responding and initiating social contact with other children

12) Eating

- Needs complete assistance with eating
- Eats with fingers
- Can use some utensils (e.g. spoon, chopstick) but may be messy
- Eats completely independently with proper use of all utensils (e.g. spoon, chopstick)

13) Toileting

- Wears diapers day and night
- Wears diaper but indicates when needs changing
- Indicates or asks to use toilet, but does not go independently
- Toilet trained in daytime (occasional accidents); wears diaper or pull up at night
- Completely toilet trained day and night

14) Dressing

- Needs complete assistance dressing and undressing
- Cooperates with dressing (e.g. raising arms, etc.)
- Can remove or pull on/up clothes
- Can dress self quite well but needs help with buttons, zippers, etc.
- Can dress and undress self completely

15) Self-injurious behaviour (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behaviour remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person. How often in the past 2 months have you seen these behaviours in your child?

- Never

Monthly
Weekly
Daily
Hourly

16) Stereotyped behaviours look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage. How often in the past 2 months have you seen these behaviours in your child?

Never
Monthly
Weekly
Daily
Hourly

17) Aggressive or destructive behaviours are offensive actions or deliberate overt attacks directed towards other individuals or objects. They occur repeatedly in the same way over and over again, and they are characteristic for that person. How often in the past 2 months have you seen these behaviours in your child?

Never
Monthly
Weekly
Daily
Hourly

Child's Social Abilities

This section is about your child's social abilities.

<<Questions from the Social Communications Questionnaire>>

Section III: Autism

For the following section, we would like to know about your views about autism.

1. Compared to the general population, how would you rate your knowledge about autism as a developmental disorder?

Much lower than the general population
Lower than the general population
Same as the general population
Higher than the general population
Much higher than the general population

2. For the following statements, please check either “True”(T) or “False”(F) for the following questions. We encourage you to make your best guess, but if you are completely unsure of an answer you may circle “Don’t Know”(DK)

Statement	True	False	I don't know
A. The earliest signs of autism include poor response to being called by name and lack of pointing.			
B. Most children with autism also have special abilities (e.g. good memory, good at math)			
C. Children with autism are good at understanding the thoughts, feelings, and intentions of other people.			
D. Children with autism do not always, but may, have intellectual disability.			
E. Autism affects children of all racial, ethnic and social class backgrounds with equal frequency.			
F. Autism can be cured.			
G. Children with autism range from being nonverbal to being verbal.			
H. Children with autism are known to have a wide variety of interests and good social skills.			
I. Children with autism may communicate using sign language or pictures.			
J. Children with autism usually engage in play that looks like that of other children their age.			

K. What do you think are the causes of Autism?

Please write: _____

3) For the following statements, please check the column most applicable to you: 1 = Strongly disagree, 2 = disagree, 3 = neither disagree nor agree, 4 = agree, 5 = strongly agree

Statement	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
1. Even though my child has Autism, he/she can still achieve many things					
2. My child can still have a happy life					

3. I feel like my child's autism is my fault					
4. It is the government's responsibility to provide appropriate services for autism					
5. I feel a lot of stress due to my child's autism					
6. My family members are a source of support for me whenever I need help for my child with autism					
7. When we go to a public place, people treat my child negatively (i.e. ignore, scold, make fun of)					
8. My friends are a source of support for me whenever I need help for my child with autism					
9. I believe that the higher the number of medical treatments my child uses, the better my child's outcome will be					
10. I believe that the higher the number of therapy services my child uses, the better my child's outcome will be					
11. I am very confident about deciding which service and treatment to use for my child					

4) In your community, how do people generally treat individuals with autism?

Section IV: Applied Behaviour Analysis

For the following section, we would like to know about your views about applied behaviour analysis (ABA).

1) Compared to the general population, how would you rate your knowledge about the principles of ABA?

- Much lower than the general population
- Lower than the general population
- Same as the general population
- Higher than the general population
- Much higher than the general population

2) For the following statements, please check either “True”(T) or “False”(F) for the following questions. We encourage you to make your best guess, but if you are completely unsure of an answer you may circle “Don’t Know”(DK).

Statement	True	False	Don’t Know
A. After a child has mastered a task with prompting, prompts should be faded so that the child can eventually demonstrate the skill independently.			
B. There is no scientific evidence showing the benefits of ABA.			
C. ABA is only used with the child during sessions and parents should not try to continue the therapy at home.			
D. In ABA it is often best to teach the child a complex task by breaking it down into parts rather than teaching the task as a whole.			
E. ABA is best used with other types of therapies (such as acupuncture, SSRI).			
F. In ABA, you should not vary the teaching materials or the wording of the instruction because this will just confuse the child.			
G. At the start of therapy most children respond just as well to praise (e.g., someone saying “good job!”) as to tangible reinforcers or rewards (e.g., candy).			
H. 4 hours a week of ABA therapy is the same effectiveness as 20 hours a week of ABA therapy			
I. ABA is beneficial for working on social and behavioral difficulties.			

3) For the following statements, please check the column most applicable to you: 1 = Strongly disagree, 2 = disagree, 3 = neither disagree nor agree, 4 = agree, 5 = strongly agree

Statement	Strongly Disagree	Disagree	Don’t know	Agree	Strongly Agree
N. I believe that ABA is a major breakthrough in the treatment of autism.					
O. I am convinced that ABA I will turn out to be another false miracle like other “miracle cures” for autism.					
P. I believe that medical treatments are more					

effective than ABA therapy.					
Q. I believe that ABA is likely to result in permanent improvement for children with autism.					
R. I feel comfortable with the procedures and techniques used in ABA therapy.					
S. I am skeptical about 'success stories' that I hear about the use of ABA for children with autism.					
T. I believe that ABA helps children with autism to improve more than any other form of intervention.					
U. No matter what, I will always continue to use behavioural principles with my child with autism.					
V. I believe that ABA will help my child to develop better social and play skills.					
W. I believe that ABA will help my child to develop better academic skills.					
X. I believe that ABA will help my child to develop better communication skills.					
Y. I believe that ABA will help my child to develop better self-help skills.					
Z. I believe that ABA will help to eliminate or reduce my child's problem behaviour (e.g., tantruming, self-injury, and/or aggression).					

Section V: Taiwan Services

The following questions refer to ABA services, medical treatments, education, and other services for children with autism in Taiwan.

ABA services:

There are many different types of ABA such as Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI) and Pivotal Response Training (PRT). Please answer the following based on your experiences with ABA services.

1. Please check off the statement that best applies to your child

My child is currently receiving ABA services-please complete question 2 and proceed to the next section

My child used to receive ABA services but has stopped-please complete question 2 and 3 and proceed to the next section

My child has never received ABA services-please complete question 3 only

2. A) How frequently does/did your child receive ABA therapy?

less than or equal to 2 hours a week

between 2 to 4 hours a week

between 5 to 7 hours a week

between 8 to 10 hours a week

between 11 to 13 hours a week

between 14 to 16 hours a week

between 17 to 19 hours a week

20 or more hours a week

- B) How long has/did your child receive ABA therapy?

less than or equal to 1 month

between 1 to 3 months

between 4 to 6 months

between 7 to 9 months

between 10 to 12 months

13 months or longer (please specify _____)

- 3.If your child has never received ABA or has stopped ABA, please specify the reasons why (please check all that apply):

Service was too expensive

Service was too far

Did not see improvement in child

Wanted to try something else

Other (Please specify: _____)

Please complete the following section if your child is currently receiving ABA or has previously received ABA.

For questions 1 and 2, please use the following criteria to rate your child's abilities:

- 1 (low) = nonverbal and delays in all areas
- 3 (medium) = some language and delays in many areas
- 5 (high) = verbal and some skills on par with children his/her age

1. How would you rate your child's functioning when he/she started ABA intervention?

1	2	3	4	5
low		medium		high

2. How would you rate your child's functioning now?

1	2	3	4	5
low		medium		high

3. Your child's level of functioning could change (up or down) for many reasons (e.g., ABA, other interventions, natural developmental changes, etc.) To what extent would you say that the change in your child's functioning, if any, is related to your child's participation in an ABA program?

1	2	3	4	5	n/a
not at all		moderately		extremely	no change

For questions 4-8 please circle the number/statement that best corresponds with your child's progress:

4. How would you rate your child's improvement in **social and play skills** since the ABA intervention began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

5. How would you rate your child's improvement in **academic skills** since the ABA intervention began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

6. How would you rate your child's improvement in **communication skills** since the ABA intervention began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

7. How would you rate your child's improvement in **self-help skills** since the ABA intervention began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

8. How would you rate your child's improvement in **problem behaviours** since the ABA intervention began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

9. Overall, how satisfied are you with your child's **ABA services**?

Very Dissatisfied

Dissatisfied

Neutral (Neither satisfied or dissatisfied)

Satisfied

Very Satisfied

Medical Treatments

1)

Please check the type of medical treatment your child has/is using:

Medical Treatment	Never used	Used before but stopped	Currently Using
A. SSRI (Selective Serotonin Reuptake Inhibitors)			
B. Special Diets			
C. Vitamin Supplements			
D. Chelation therapy (i.e. removing mercury from body)			

E. Acupuncture			
F. Ritalin/Concerta			
G. Other (please specify)			

1b) Overall, how satisfied are you with the **current medical treatments your child is using?**

- Very Dissatisfied
- Dissatisfied
- Neutral (Neither satisfied or dissatisfied)
- Satisfied
- Very Satisfied

2) If you used medical treatments and then stopped, what are the reasons for stopping (please check all that apply)?

- Service was too expensive
- Service was stopped by the medical professional
- Service was too far
- Did not see improvement in child
- Wanted to try something else
- Other (Please specify: _____)

3) When choosing a medical treatment for your child, what factors do you consider? (Please check all that apply)

- Cost
- Distance from home/work
- Scientific evidence
- Recommendation from medical professionals
- Recommendation from school/other service professionals
- Recommendation from family
- Recommendation from friends
- Recommendation from religious leaders
- Recommendation from celebrities
- TV program sources
- Internet sources
- Book sources
- Other: _____

Services in school:

1) What type of school is your child in?
Regular Classroom only

Regular classroom + resource room service
 Regular classroom + itinerant service
 Both Special Education and Regular Classroom
 Special Education Classroom
 Special Education School for Children with Disabilities
 My child is not in school (Please specify reason(s) why:
 _____)

2) What services are currently being used by your child at school? (check all that apply)

No services are offered at my child's school

Occupational therapy

Physical therapy

Speech therapy

Other (Please specify: _____)

3) Overall, how satisfied are you with the services your child receives in school?

Very Dissatisfied

Dissatisfied

Neutral (Neither satisfied or dissatisfied)

Satisfied

Very Satisfied

Services outside of school:

1) **Among the following services outside of school**, which of them (1) do you know are available in your city/town, (2) do you currently use or have used in the past, and (3) do you need? Please check accordingly

Service	Available in my city/town and we currently use	Available in my city/town and we have used in the past but have now stopped	Not available in my city/town but we need
A. Physical therapy			
B. Occupational therapy			
C. Sensory Integration Therapy			
D. Parent Training			
E. Parent Support Services			
F. Respite Care			
G. Speech Therapy			
H. Music Therapy			

I. Art Therapy			
J. Pet Therapy			
K. Hypnotherapy			
L. Facilitated Communication (typing training)			
M. Relationship development intervention (RDI)			

If there are **services outside of school** that are being used/needed but not in the list, please specify:

Please list other services that you are currently using: _____

Please list other services that are not available, but you need: _____

2) Overall, how satisfied are you with the **current services your child is using**?

Very Dissatisfied

Dissatisfied

Neutral (Neither satisfied or dissatisfied)

Satisfied

Very Satisfied

3) If you used services and then stopped, what are the reasons for stopping (please check all that apply)?

Service was too expensive

Service was stopped by the medical professional

Service was too far

Did not see improvement in child

Wanted to try something else

Other (Please specify: _____)

4) When looking for a service for your child, what are factors you consider? (please check all that apply)

Cost

Distance from home/work

Scientific evidence

Recommendation from medical professionals

Recommendation from school/other service professionals

Recommendation from family

Recommendation from friends

Recommendation from religious leaders

Recommendation from celebrities
 TV program sources
 Internet sources
 Book sources
 Other _____

5)

a) Out of all the services your child has received or is currently receiving, which service/intervention do you think has contributed to the most improvement for your child?

b) For the following questions, please answer based on the service/intervention you wrote previously.

How would you rate your child's functioning when he/she started intervention?

1	2	3	4	5
low		medium		high

c) How would you rate your child's functioning now?

1	2	3	4	5
low		medium		high

d) Your child's level of functioning could change (up or down) for many reasons (e.g. other interventions, natural developmental changes, etc.) To what extent would you say that the change in your child's functioning, if any, is related to your child's participation in this service?

1	2	3	4	5	n/a
not at all		moderately		extremely	no change

e) How would you rate your child's improvement in **social and play skills** since this service began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

f) How would you rate your child's improvement in **academic skills** since this service began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

g) How would you rate your child's improvement in **communication skills** since this service began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

h) How would you rate your child's improvement in **self-help skills** since this began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

i) How would you rate your child's improvement in **problem behaviours** since this service began?

1	2	3	4	5
Got worse	No improvement	Slightly improved	Somewhat improved	Substantially improved

Additional Questions:

1) Please add in any additional comments you may have about this survey or about obtaining services for your child with ASD.

Thank you very much for taking the time to complete this questionnaire!

Appendix B

台灣泛自閉症服務問卷調查

加拿大約克大學 Dr. Adrienne Perry and Ms. Hilda Ho 與國立臺灣師範大學特殊教育學系王慧婷教授合作一項計畫，此計畫將探討有自閉症孩子的家長會為孩子選擇何種服務。此研究的目的為整合育有自閉症孩子的家長已使用、正在使用及未來可能使用的服務。此研究也會探討家長對於自閉症及自閉症服務的認識及瞭解。此研究結果將助於精進當前的自閉症服務並為未來相關政策提供建議。

參加資格

我們誠摯地邀請有 18 歲以下確診為或疑似自閉症兒童或診斷為發展遲緩疑似自閉症，並且目前住在台灣的家長完成此匿名調查。此問卷為中文且可以以線上或紙本方式作答。

參與內容

此研究需填寫 35 到 45 分鐘的問卷。請您依照您對自閉症的認識與了解及任何您孩子曾經使用、正在使用及未來將會使用的自閉症服務進行填寫。

自願性參與

此研究為自願性參與。若您選擇不參與或想中途退出，皆不影響您孩子所接受的服務。

保密及隱私

您將不需提供名字或是任何可識別身分之資料，而您給予我們的所有資訊將會保密。

風險及利益

我們並未預期參與此研究會有任何風險。當完成這的調查之後，您將在兩個星期之內收到台幣 150 元之禮卷，您也會有機會參與下個關於台灣家長對於自閉症相關服務的想法研究。

倫理審查

此計畫已被約克大學倫理審查小組(the Human Participants Review Sub-Committee for compliance with Senate ethics policy) 檢視及同意。若您對此研究的倫理及同意過程有任何問題，您可以透過 email 及電話連絡約克大學研究倫理辦公室。Email: ore@yorku.ca 或電話: 1(416) 736-2100 ext. 55201.

如果有其他問題或是想進一步了解此計畫的相關問題，請與 Ms. Hilda Ho 聯繫。Email : hildaho@yorku.ca.

- ☐ 我同意，我想參加
- ☐ 我不同意，我不想參加

該調查問卷有幾個不同的部分，由被診斷患有疑似自閉症或患有自閉症的兒童的父母或主要照顧者填寫。 本研究的目的是了解台灣患有自閉症的兒童父母和照顧者所使用的服務類型。此研究將不會對於您孩子所接受之任何服務有影響。

A1 家庭背景:第一部分是為了幫助我們了解填寫者的背景。 雙親家庭一個人可以為其配偶填寫兩方的資訊。資訊以填寫者為主。

A1.1 您與患有自閉症的孩子有什麼關係？

- ☐ 1. 親生父母
 ☐ 3. 繼父母
 ☐ 5. 監護人
☐ 2. 收養父母
 ☐ 4. 祖父母
 ☐ 6. 其他 (請註明:) _____

A1.2 您的性別是？

- ☐ 1. 男性
 ☐ 2. 女性
 ☐ 3. 其他 (請註明:) _____

A1.3 您的婚姻狀況如何？

- ☐ 1. 已婚
 ☐ 3. 分居，離異，或是喪偶
☐ 2. 單親父母
 ☐ 4. 其他 (請註明:) _____

A1.4 同住之家庭成員有？（請選擇所有適用選項）

- | | |
|--|---|
| ☐ 1. 兒童的親生母親 | ☐ 5. 兒童的祖父母（們）
請註明具體數量:) _____ |
| ☐ 2. 兒童的親生父親 | ☐ 6. 保姆 |
| ☐ 3. 兒童 | ☐ 7. 其他
請註明是誰以及他們與孩童的關係: _____ |
| ☐ 4. 兒童的兄弟姐妹（們）
請註明具體數量: _____ | |

A1.5 家裡最常用的語言是什麼？

- ☐ 1. 國語
 ☐ 4. 原住民語言
 請註明: _____
☐ 2. 台語
 ☐ 5. 其他
 請註明: _____
☐ 3. 客語

	請填寫您及您配偶的基本資訊	
	1. 您的	2. 您的配偶
A2.1 您的/您的配偶出生日期為何?	____月/____西元年	____月/____西元年
A2.2 您的/您的配偶國籍身分是什麼?	☐ 1. 台灣 ☐ 2. 其他 請註明: _____	☐ 1. 台灣 ☐ 2. 其他 請註明: _____
A2.3 您的/您的配偶宗教信仰是什麼?	☐ 1. 道教 ☐ 2. 佛教 ☐ 3. 基督教 ☐ 4. 天主教 ☐ 5. 伊斯蘭教 ☐ 6. 無宗教信仰 ☐ 7. 其他 (請註明: _____)	☐ 1. 道教 ☐ 2. 佛教 ☐ 3. 基督教 ☐ 4. 天主教 ☐ 5. 伊斯蘭教 ☐ 6. 無宗教信仰 ☐ 7. 其他 (請註明: _____)
A2.4 您/您的配偶已完成的最高教育階段是什麼?	☐ 1. 小學 ☐ 2. 中學 ☐ 3. 高中 ☐ 4. 專科 / 大學 ☐ 5. 碩士及以上	☐ 1. 小學 ☐ 2. 中學 ☐ 3. 高中 ☐ 4. 專科 / 大學 ☐ 5. 碩士及以上
A2.5 您/您的配偶職業狀況是?	☐ 1. 全職員工 ☐ 2. 兼職員工 ☐ 3. 未被雇用但在求職中 ☐ 4. 未被雇用 ☐ 5. 全職媽媽 / 全職爸爸 ☐ 6. 同時兼職幾個工作	☐ 1. 全職員工 ☐ 2. 兼職員工 ☐ 3. 未被雇用但在求職中 ☐ 4. 未被雇用 ☐ 5. 全職媽媽 / 全職爸爸 ☐ 6. 同時兼職幾個工作

A2.6	請註明具體職業： _____	請註明具體職業： _____
A3.1 您有幾個孩子？（如果您是孩子的監護人，請回答您是幾個孩子的主要照顧者） ☐ 1 ☐ 2 ☐ 3 ☐ 4 個或以上 （請註明具體人數： _____）		

A3.2 您有幾個被診斷患有自閉症或者疑似自閉症的兒童？ ☐ 1 ☐ 2 ☐ 3 ☐ 4 個或以上 （請註明具體人數： _____）
--

B1 兒童背景: 在這個部分中，我們希望能了解更多有關您孩子的背景。如果您有超過一名患有自閉症或疑似自閉症的兒童，請根據您診斷患有自閉症 / 疑似自閉症的第一個孩子填寫以下調查表。

B1.1 這名兒童是：	☐ 1. 男孩	☐ 2. 女孩
B1.2 您孩子的出生日期是？	_____ 月 / _____ 西元年	
B1.3 您孩子的診斷結果是？	☐ 1. 疑似自閉症（含發展遲緩疑似自閉症） （請註明他們收到診斷結果的時間： _____ 月 / _____ 西元年） ☐ 2. 自閉症 （請註明他們收到診斷結果的時間： _____ 月 / _____ 西元年）	
B1.4 您的孩子是否有以下任何一種情況（請選擇所有適用選項）		
☐ 1. 腿部使用困難（例如，走路，跑步，站立 - 步態闌珊不算在內） ☐ 2. 手部使用困難（例如，撿拾東西，拿鉛筆） ☐ 3. 有其他相關運動控制/協調的問題 ☐ 4. 癲癇	☐ 5. 視力障礙 ☐ 6. 聽力障礙 ☐ 7. 有餵養或進食困難（胃腸問題，餵食管，食物過敏等） ☐ 8. 心臟問題	☐ 9. 哮喘或其他呼吸道疾病 ☐ 10. 身體畸形（不尋常的面部，頭部，眼睛，耳朵，手指，腳趾） ☐ 11. 其他（請註明：） _____
B2 兒童的日常生活能力: 以下問題與您孩子的日常生活能力有關。 *問題改編自 GO4KIDDS 自適應行為量表 (Perry 等, 2015) 和智能障礙人士的行為問題清單 (Rojahn, 2011)		
B2.1 您的孩子需要多大程度的幫助或支持（例如，上廁所，穿衣，吃飯等）？		

- | | |
|--|--|
| ☐ 1. 在生活中幾乎所有面向都需要支持 | ☐ 4. 在生活中少數的面向需要支持 |
| ☐ 2. 在生活中大部分的面向需要支持 | ☐ 5. 不需要幫忙 |
| ☐ 3. 在生活中某些面向需要支持 | |

B2.2 您的孩子對口語的理解程度是多少？

- | | |
|--|--|
| ☐ 1. 能夠理解很少的口語 | ☐ 4. 能夠理解大多數例行日常用語 |
| ☐ 2. 能夠在熟悉的環境中理解一些基本語言和簡單的指令（例如坐下） | ☐ 5. 能夠理解有關廣泛話題的複雜語言 |
| ☐ 3. 能夠理解最基本的指示和問題 | |

B2.3 您的孩子使用多少口語進行溝通？

- | | |
|---|--|
| ☐ 1. 能夠使用極少有意義的話語 | ☐ 4. 能夠有意義地在有限的話題範圍內進行溝通 |
| ☐ 2. 能夠溝通基本需求和需要 | ☐ 5. 能夠有意義地溝通廣泛的話題 |
| ☐ 3. 能夠溝通需求，需要和一些想法 | |

B2.4 您的孩子是否使用擴大性替代性溝通系統進行溝通？（包括手語，圖片交換溝通系統，語音輸出設備等）

- ☐ 1. 不，不使用任何替代系統
- ☐ 2. 是的，使用擴大性替代性溝通系統進行溝通
（請註明：_____）

您的孩子使用此系統的溝通情況如何？

- | |
|--|
| ☐ 1. 能夠使用極少有意義的話語 |
| ☐ 2. 能夠溝通基本需求和需要 |
| ☐ 3. 能夠溝通需求和一些想法 |
| ☐ 4. 能夠有意義地在有限的話題範圍內進行溝通 |
| ☐ 5. 能夠有意義地溝通廣泛的話題 |

B2.5 您的孩子與親近的成年人進行社交互動的程度是多少？

- | | |
|--|---|
| ☐ 1. 對於親近的成年人進行社交互動幾乎沒有興趣 | ☐ 4. 顯示出明顯的社會興趣，經常回應他人，並且有時會向親近的成年人開啟社交互動 |
| ☐ 2. 顯示出有限的社會興趣，但有時會回應親近的成年人 | |

☐ 3. 顯示一些社會興趣，會回應他人但不會向親近的成年人開啟社交互動	☐ 5. 參與廣泛的社交互動，其中包括回應他人和向親近的成年人開啟社交接觸						
B2.6 您的孩子與其他兒童進行社交互動的程度是多少？ <table border="0"> <tr> <td data-bbox="191 409 812 514"> ☐ 1. 對與其他兒童的社交互動幾乎沒有興趣 </td> <td data-bbox="812 409 1429 514"> ☐ 4. 表現出明顯的社會興趣，回應他人，並且有時會向其他兒童開啟社交互動 </td> </tr> <tr> <td data-bbox="191 514 812 619"> ☐ 2. 顯示出有限的社會興趣，但有時會回應其他兒童 </td> <td data-bbox="812 514 1429 619"> ☐ 5. 參與廣泛的社交互動，其中包括回應他人和向其他兒童開啟社交接觸 </td> </tr> <tr> <td data-bbox="191 619 812 693"> ☐ 3. 顯示出一些社會興趣，會回應他人，但不會向其他兒童開啟社交互動 </td> <td></td> </tr> </table>		☐ 1. 對與其他兒童的社交互動幾乎沒有興趣	☐ 4. 表現出明顯的社會興趣，回應他人，並且有時會向其他兒童開啟社交互動	☐ 2. 顯示出有限的社會興趣，但有時會回應其他兒童	☐ 5. 參與廣泛的社交互動，其中包括回應他人和向其他兒童開啟社交接觸	☐ 3. 顯示出一些社會興趣，會回應他人，但不會向其他兒童開啟社交互動	
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B2.7 進食 <table border="0"> <tr> <td data-bbox="191 735 812 798"> ☐ 1. 需要完整的進食幫助 </td> <td data-bbox="812 735 1429 798"> ☐ 3. 可以使用一些器具（如勺子，筷子），但可能會吃得很亂 </td> </tr> <tr> <td data-bbox="191 798 812 861"> ☐ 2. 用手指吃 </td> <td data-bbox="812 798 1429 861"> ☐ 4. 正確使用所有器具（如勺子，筷子），可以完全獨立地吃 </td> </tr> </table>		☐ 1. 需要完整的進食幫助	☐ 3. 可以使用一些器具（如勺子，筷子），但可能會吃得很亂	☐ 2. 用手指吃	☐ 4. 正確使用所有器具（如勺子，筷子），可以完全獨立地吃		
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B2.8 如廁 <table border="0"> <tr> <td data-bbox="191 966 812 1029"> ☐ 1. 白天和晚上都穿著尿布 </td> <td data-bbox="812 966 1429 1029"> ☐ 4. 白天有訓練好的如廁習慣（含偶爾發生意外）；晚上穿尿布 </td> </tr> <tr> <td data-bbox="191 1029 812 1092"> ☐ 2. 但能表明何時需要更換 </td> <td data-bbox="812 1029 1429 1092"></td> </tr> <tr> <td data-bbox="191 1092 812 1165"> ☐ 3. 能表明或要求使用廁所，但不能獨立使用 </td> <td data-bbox="812 1092 1429 1165"> ☐ 5. 白天和晚上都有完全訓練好的如廁習慣 </td> </tr> </table>		☐ 1. 白天和晚上都穿著尿布	☐ 4. 白天有訓練好的如廁習慣（含偶爾發生意外）；晚上穿尿布	☐ 2. 但能表明何時需要更換		☐ 3. 能表明或要求使用廁所，但不能獨立使用	☐ 5. 白天和晚上都有完全訓練好的如廁習慣
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B2.9 穿衣 <table border="0"> <tr> <td data-bbox="191 1207 812 1270"> ☐ 1. 需要完全的穿衣和脫衣幫助 </td> <td data-bbox="812 1207 1429 1270"> ☐ 4. 能夠很好地自己穿衣服但是需要子，拉拉鍊等幫助 </td> </tr> <tr> <td data-bbox="191 1270 812 1333"> ☐ 2. 協助穿衣（例如：舉起手臂等） </td> <td data-bbox="812 1270 1429 1333"> ☐ 5. 能夠完全自主地穿衣和脫衣 </td> </tr> <tr> <td data-bbox="191 1333 812 1365"> ☐ 3. 可以脫掉或者拉起衣服 </td> <td></td> </tr> </table>		☐ 1. 需要完全的穿衣和脫衣幫助	☐ 4. 能夠很好地自己穿衣服但是需要子，拉拉鍊等幫助	☐ 2. 協助穿衣（例如：舉起手臂等）	☐ 5. 能夠完全自主地穿衣和脫衣	☐ 3. 可以脫掉或者拉起衣服	
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☐ 3. 可以脫掉或者拉起衣服							
B2.10 自傷行為會對當事者身體造成傷害。自傷行為常以相同的方式反覆出現，並且它們已經成為該人的特徵。您在過去的 2 個月內有多常看到您的孩子存在這些行為？ <table border="0"> <tr> <td>☐ 1. 從未有過</td> <td>☐ 2. 每月</td> <td>☐ 3. 每週</td> <td>☐ 4. 每天</td> <td>☐ 5. 每小時</td> </tr> </table>		☐ 1. 從未有過	☐ 2. 每月	☐ 3. 每週	☐ 4. 每天	☐ 5. 每小時	
☐ 1. 從未有過	☐ 2. 每月	☐ 3. 每週	☐ 4. 每天	☐ 5. 每小時			
B2.11 刻板行為對普通人來說是不尋常，怪異或者不合時宜。它們一次又一次以同樣的方式重複出現的自發行為，成為該人的特徵。但是，它們不會造成身體傷害。您在過去的 2 個月內有多常看到您的孩子存在這些行為？ <table border="0"> <tr> <td>☐ 1. 從未有過</td> <td>☐ 2. 每月</td> <td>☐ 3. 每週</td> <td>☐ 4. 每天</td> <td>☐ 5. 每小時</td> </tr> </table>		☐ 1. 從未有過	☐ 2. 每月	☐ 3. 每週	☐ 4. 每天	☐ 5. 每小時	
☐ 1. 從未有過	☐ 2. 每月	☐ 3. 每週	☐ 4. 每天	☐ 5. 每小時			
B2.12 攻擊性或破壞性行為是針對其他人或物體的冒犯性行為或是蓄意的明顯攻擊。它們一次又一次以同樣的方式重複出現，成為該人的特徵。您在過去的 2 個月內有多常看到您的孩子存在這些行為？							

- ☐ 1. 從未有過 ☐ 2. 每月 ☐ 3. 每週 ☐ 4. 每天 ☐ 5. 每小時

S1 兒童的社交能力 這個部分是有關與您孩子的社交能力。

社交溝通問卷 (SCQ) Michael Rutter, M.D., F.R.S., Anthony Bailey, M.D., Sibel Kazak Berument, Ph.D., Catherine Lord, Ph.D., and Andrew Pickles, Ph.D.

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C1 自閉症: 對於以下部分，我們想了解您對自閉症的看法。		
C1.1 與一般人相比，您如何評價您對自閉症發展障礙的知識程度？		
☐ 1. 遠低於一般人群	☐ 4. 高於一般人群	
☐ 2. 低於一般人群	☐ 5. 遠高於一般人群	
☐ 3. 與一般人群相同		
C1.2 對於以下陳述，請在以下問題的“是”或“否”打勾。果您完全不確定某個答案，可以選擇“不知道”。		
	是	否
自閉症的最早跡象包括被叫到名字時的缺乏反應和缺乏用食指指東西的行	☐	☐
大多數患有自閉症的兒童也有特殊能力（例如記憶力好，擅長數學）。	☐	☐
患有自閉症的兒童善於理解其他人的想法，感受和意圖。	☐	☐
患有自閉症的兒童並不總是但也許有智能障礙。	☐	☐
自閉症以同樣的好發率影響所有種族，所有民族，和所有社會階層背景的兒	☐	☐
自閉症可以被治癒。	☐	☐
自閉症兒童的症狀範圍是從不說話的，到說話的都有。	☐	☐
眾所周知，患有自閉症的兒童具有廣泛的興趣和良好的社交技能。	☐	☐
患有自閉症的兒童也許使用手語或圖片進行溝通。	☐	☐
患有自閉症的兒童通常會參與其他同齡孩子的遊戲。	☐	☐
C1.3 您認為導致自閉症的原因是什麼？ 請填寫：		

C1.4 對於以下陳述，請在最適用於您狀況的一欄內打勾(非常不同意；不同意；一般；同意；非常同意)。

	非常不同意	不同意	一般	同意	非常同意
A) 即使我的孩子患有自閉症，他/她仍然可以實踐很多事情	☐	☐	☐	☐	☐
B) 我的孩子仍然可以擁有一個快樂的生活	☐	☐	☐	☐	☐
C) 我覺得我小孩的自閉症是我的過錯	☐	☐	☐	☐	☐
D) 政府有責任為自閉症提供合適的服務項目	☐	☐	☐	☐	☐
E) 因為我的小孩有自閉症，我感受到很多的壓力	☐	☐	☐	☐	☐
F) 每次我的自閉症孩子需要幫助的時候，我的家人是支持我的來源	☐	☐	☐	☐	☐
G) 當我們去公共場所時，人們負面對待我的孩子（比如，忽略，責罵，取笑）	☐	☐	☐	☐	☐
H) 每次當我的自閉症孩子需要幫助的時候，我的朋友是支持我的來源	☐	☐	☐	☐	☐
I) 我相信我的孩子使用的醫療數量越多，我的孩子會有更好的效果	☐	☐	☐	☐	☐
J) 我相信我的孩子使用的療育服務數量越多，我的孩子會有更好的成果	☐	☐	☐	☐	☐
K) 我對於為我孩子決定使用何種服務及醫療感到很有信心	☐	☐	☐	☐	☐

C1.5 在您的生活中，人們通常如何對待患有自閉症的人？
請填寫：

D1 應用行為分析:對於以下部分，我們想了解您對應用行為分析（ABA）的看法。

D1.1 與一般人相比，您如何評價您對 ABA 原則的知識程度？

☐ 1. 遠低於一般人群 ☐ 2. 低於一般人群 ☐ 3. 與一般人群相同	☐ 4. 高於一般人群 ☐ 5. 遠高於一般人群
---	---

D1.2 對於以下陳述，請在以下問題的“是”或“否”打勾。如果您完全不確定某個答案，可以選擇“不知道”。

	是	否	不知道
A) 在孩子掌握了帶有提示的任務後，應該逐漸撤除提示，這樣孩子才能最終獨立地展示技能。	☐	☐	☐
B) 沒有科學證據證明 ABA 的好處。	☐	☐	☐
C) ABA 僅用於兒童治療期間，父母不應該在家中繼續嘗試。	☐	☐	☐
D) 在 ABA 中，當教導孩子一個複雜的任務時，通常最好把任務分解成很多部分，而不是直接用整體下去教。	☐	☐	☐
E) ABA 最好跟其他類型的治療結合（例如針灸，服用抗憂鬱劑）。	☐	☐	☐
F) 在 ABA 中，你不應該使用不一樣的教材或者教學的措辭，因為這樣會使孩子感到困擾。	☐	☐	☐
G) 在治療的起初，大多數孩子會對誇獎（例如，某個人稱讚“你真棒！”和有形獎賞（例如，糖果）做出同樣的反應。	☐	☐	☐
H) 一週四個小時的 ABA 治療與一週 20 個小時的 ABA 治療效果相同。	☐	☐	☐

D2.1 對於以下陳述，請在最適用於您狀況的一欄內打勾（非常不同意；不同意；一般；同意；非常同意）。

	非常不同意	不同意	一般	同意	非常同意
A) 我相信 ABA 是治療自閉症的重大突破。	☐	☐	☐	☐	☐
B) 我認為 ABA 會成為像其他自閉症的“奇蹟療法”一樣的虛假。	☐	☐	☐	☐	☐
C) 我相信醫學治療比 ABA 治療更加有效。	☐	☐	☐	☐	☐
D) 我相信 ABA 很有可能給患有自閉症的兒童帶來永久性的改善。	☐	☐	☐	☐	☐
E) 我對 ABA 治療用到的程序和技術覺得安心。	☐	☐	☐	☐	☐
F) 我對於聽過的關於 ABA 應用於自閉症兒童的「成功故事」持懷疑態度。	☐	☐	☐	☐	☐
G) 我相信 ABA 會比其他任何形式的介入措施給患有自閉症的兒童帶來更多的改善。	☐	☐	☐	☐	☐
H) 無論如何，我會一直繼續對我患有自閉症的孩子使用行為學派原則。	☐	☐	☐	☐	☐
I) 我相信 ABA 會幫助我的孩子培養更好的社交和遊戲技能。	☐	☐	☐	☐	☐
J) 我相信 ABA 會幫助我的孩子培養更好的學術技能。	☐	☐	☐	☐	☐
K) 我相信 ABA 會幫助我的小孩培養更好的溝通技巧。	☐	☐	☐	☐	☐
L) 我相信 ABA 會幫助我的小孩培養更好的自理技能。	☐	☐	☐	☐	☐
M) 我相信 ABA 會幫助消除或減少我孩子的行為問題（例如，亂發脾氣，自我傷害，和/或攻擊性）	☐	☐	☐	☐	☐

D3 台灣服務： 以下問題涉及台灣的 ABA 服務，醫療，教育和其他關於自閉症兒童的服務。**ABA 服務：** ABA 包含許多不同的類型，例如單一嘗試訓練（DTT），早期密集行為介入（EIBI）和核心反應訓練（PRT）。請根據您對 ABA 服務的經驗回答以下問題。

D3.1 請選擇最適合您孩子情況的陳述：

- ☐ 1. 我的孩子目前正在接受 ABA 服務（請完成 D3.2 及 D3.3 題，跳過 D3.4 並直接至 D4 作答）
 ☐ 2. 我的孩子曾經接受 ABA 服務但已經停止
 ☐ 3. 我的孩子從未接受過 ABA 服務，請跳到第 D3.4 題。

D3.2 您的孩子現在/過去接受 ABA 治療的頻率/次數是多少？

- ☐ 1. 每周少於或等於 2 小時 ☐ 4. 每週 8 到 10 個小時 ☐ 7. 每週 17 到 19 個小時
☐ 2. 每週 2 到 4 個小時 ☐ 5. 每週 11 到 13 個小時 ☐ 8. 每週 20 小時或更長時間
☐ 3. 每週 5 到 7 個小時 ☐ 6. 每週 14 到 16 個小時

D3.3 您的孩子現在/過去接受 ABA 治療多久了？

- ☐ 小於或等於 1 個月 ☐ 4 到 6 個月之間 ☐ 10 到 12 個月之間
☐ 1 到 3 個月之間 ☐ 7 到 9 個月之間 ☐ 13 個月或更長時間（請註明：）

D3.4 如果您的孩子從未接受過 ABA 或者已停止 ABA，請說明原因（請在所有適用的選項前打勾）：

- ☐ 1. 服務太貴了 ☐ 4. 想嘗試其他的東西
☐ 2. 服務距離太遠了 ☐ 5. 其他（請註明：_____
☐ 3. 沒有看到小孩的改善

D4 此部分有關於您孩子所接受的 ABA 服務。若您的孩子從未接受過 ABA 服務，E1 醫療服務部分作答。

D4.1 對於問題 A 和 B，請使用以下標準評估您孩子的能力：

1（低）=非語言上的和所有領域上的落後 3（中）=一些語言上的和許多領域上的落後 5（高）=語言和一些技能同等於與他/她同年齡的孩子

A) 當您的孩子開始 ABA 治療時，您如何評價您孩子的實用性技能(例如語言、社交、溝通、生活自理)？

☐ 1(低) ☐ 2 ☐ 3(中) ☐ 4 ☐ 5(高)

B) 您如何評價您孩子現在的實用性技能(例如語言、社交、溝通、生活自理)？

☐ 1(低) ☐ 2 ☐ 3(中) ☐ 4 ☐ 5(高)

D4.2 由於多種原因（例如，ABA，其他介入措施，自然發育變化等），您孩子的能力水平可能會發生變化（上升或下降）。您認為孩子的實用性技能變化（如果有的話）在多大程度上是與參加 ABA 項目有關？

☐	☐	☐	☐	☐	☐
1	2	3	4	5	沒有變化
根本沒有		中等地		非常地	

D4.3 請回答最符合您孩子進度的數字/陳述：

A) 自 ABA 介入開始以來，您如何評價您的孩子在社交和遊戲技能方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

B) 自 ABA 介入開始以來，您如何評價您的孩子在學業技能方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

C) 自 ABA 介入開始以來，您如何評價您的孩子在溝通技巧方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

D) 自 ABA 介入開始以來，您如何評價您的孩子在自理技能方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

E) 自 ABA 介入開始以來，您如何評價您的孩子在行為問題方面的改善？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

D4.4 總體而言，您對孩子的 **ABA 服務** 有多滿意？

☐	☐	☐	☐	☐
1	2	3	4	5
非常不滿意	不滿意	普通	滿意	很滿意

E1 醫療服務

E1.1 請在您孩子正在使用/使用過的醫療服務類型處打勾：

	從未使用過	曾經使用但已停用	正在使用
A) SSRI (抗憂鬱劑)	☐	☐	☐
B) 特殊飲食	☐	☐	☐
C) 維生素營養品	☐	☐	☐
D) 螯合療法 (即去除體內汞)	☐	☐	☐
E) 針灸	☐	☐	☐
F) 利他能/專司達	☐	☐	☐
G) 如果有其他的自閉症相關 醫療服務 ，請註明：	☐	☐	☐
_____	☐	☐	☐
_____	☐	☐	☐
_____	☐	☐	☐

E1.2 總體而言，您對孩子目前使用的醫療服務方法滿意度如何？

☐	☐	☐	☐	☐
1	2	3	4	5
非常不滿意	不滿意	普通	滿意	很滿意

E1.3 如果您曾使用過醫療服務然後停止了，停止的原因是什麼（請在所有適用選項前打勾）？

- | | |
|---|---|
| ☐ 1. 服務太貴了
☐ 2. 醫療專業人員停止了服務
☐ 3. 服務距離太遠了 | ☐ 4. 沒有看到孩子的改善
☐ 5. 想嘗試其他的東西
☐ 6. 其他 |
|---|---|

請註明：

E1.4 為您的孩子選擇醫療服務時，您會考慮哪些因素？（請在所有適用選項前打勾）

- | | |
|--|---------------------------------------|
| ☐ 1. 成本 | ☐ 7. 來自朋友的推薦 |
| ☐ 2. 與家/工作的距離 | ☐ 8. 來自宗教領袖的推薦 |
| ☐ 3. 科學證據 | ☐ 9. 來自名人的推薦 |
| ☐ 4. 來自醫療專業人士的推薦 | ☐ 10. 電視節目來源 |
| ☐ 5. 來自學校/其他服務專業人士的推薦 | ☐ 11. 網路來源 |
| ☐ 6. 來自家人和親戚的推薦 | ☐ 12. 書籍來源 |
| | ☐ 13. 其他 |

請註明：_____

F1 學校內的服務：

F1.1 您的孩子在上哪種類型的學校？

- | | | |
|--------------------------------------|--------------------------------------|---|
| ☐ 1. 僅有普通班級 | ☐ 4. 特殊教育班級和普通班級 | ☐ 7. 我的孩子沒有就學
請說明原因： |
| ☐ 2. 普通班級+資源教室服務 | ☐ 5. 特殊教育班級 | _____ |
| ☐ 3. 普通班級+巡迴服務 | ☐ 6. 特殊教育學校 | _____ |
| | | _____ |

F1.2 您的孩子目前在學校使用哪些服務？（請選擇所有適用選項）

- ☐ 1. 我孩子的學校沒有提供任何服務
 ☐ 3. 物理治療
 ☐ 5. 其他（請註明：）
☐ 2. 職能治療
 ☐ 4. 語言治療
-

F1.3 總體而言，您對孩子在學校接受到的服務有多滿意？

- ☐ 1 非常不滿意
 ☐ 2 不滿意
 ☐ 3 普通
 ☐ 4 滿意
 ☐ 5 很滿意

G1 學校以外的服務：

G1.1 在校外的以下服務中，請從下列四個選項中選出一個與您自身狀況最相符的選項

	1. 在我的城市/城鎮有此服務，並且我們目前正在使用	2. 在我的城市/城鎮有此服務，我們曾經使用過但現已停用	3. 我的城市/城鎮不存在此服務但是我們需要它	4. 不需要
A) 物理治療	☐	☐	☐	☐
B) 職能治療	☐	☐	☐	☐
C) 感覺結合	☐	☐	☐	☐
D) 家長培訓	☐	☐	☐	☐
E) 家長支持服務	☐	☐	☐	☐
F) 喘息服務	☐	☐	☐	☐
G) 語言治療	☐	☐	☐	☐
H) 音樂治療	☐	☐	☐	☐
I) 藝術治療	☐	☐	☐	☐
J) 寵物治療	☐	☐	☐	☐
K) 催眠	☐	☐	☐	☐
L) 打字溝通	☐	☐	☐	☐
M) 人際關係發展介入治療（RDI）	☐	☐	☐	☐

G1.2 如果在學校以外有正在使用的/需要的但未在列表中的服務，請註明：
請列出您當前使用的其他服務：

請列出其他的在您的城市/城鎮不存在但您所需要的服務：

G1.3 總體而言，您對孩子目前正在接受的服務有多滿意？

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| 1 | 2 | 3 | 4 | 5 |
| 非常不滿意 | 不滿意 | 普通 | 滿意 | 很滿意 |

G1.4 如果您曾使用過服務然後停止了，停止的原因是什麼（請在所有適用選項前打勾）？

- | | | |
|---|---------------------------------------|--------------------------------------|
| ☐ 1. 服務太貴了 | ☐ 3. 服務距離太遠了 | ☐ 5. 想嘗試其他的東西 |
| ☐ 2. 醫療專業人員停止了服務 | ☐ 4. 沒有看到孩子的改善 | ☐ 6. 其他（請註明：） |

G1.5 當為您的孩子尋求服務時，您會考慮哪些因素？（請在所有適用選項前打勾）

- | | | |
|---|--|--------------------------------------|
| ☐ 1. 成本 | ☐ 5. 來自學校/其他服務專業人士的推薦 | ☐ 9. 來自名人的推薦 |
| ☐ 2. 與家/工作的距離 | ☐ 6. 來自家人和親戚的推薦 | ☐ 10. 電視節目來源 |
| ☐ 3. 科學證據 | ☐ 7. 來自朋友的推薦 | ☐ 11. 網路來源 |
| ☐ 4. 來自醫療專業人士的推薦 | ☐ 8. 來自宗教領袖的推薦 | ☐ 12. 書籍來源 |
| | | ☐ 13. 其他（請註明） |
- _____

H1.1 在您的孩子曾經接受或正在接受的所有服務中，您認為哪些服務/介入療法為您的孩子帶來了**最大的改善**（擇一）？

- ☐ 1. ABA（若選擇此選項，請跳過下一題，直接從 H3 開始作答。）
- ☐ 2. 物理治療
- ☐ 3. 職能治療
- ☐ 4. 家長培訓
- ☐ 5. 音樂治療
- ☐ 6. 促進溝通（打字溝通）
- ☐ 7. 藥物治療（請註明:） _____
- ☐ 其他（請註明:） _____

H2 對於以下問題，請根據您寫的服務/介入療法進行回答。請根據上一題作答。

H2.1 對於問題 A 和 B，請使用以下標準評估您孩子的能力：

- 1（低）=非語言上的和所有領域上的落後
- 3（中）=一些語言上的和許多領域上的落後
- 5（高）=語言和一些技能同等於與他/她同年齡的孩子

A) 當您的孩子開始接受介入治療時，您如何評價孩子的實用性技能？

- ☐ 1(低) ☐ 2 ☐ 3(中) ☐ 4 ☐ 5(高)

B) 您如何評價您孩子現在的實用性技能(例如語言、社交、溝通、生活自理)？

- ☐ 1(低) ☐ 2 ☐ 3(中) ☐ 4 ☐ 5(高)

H2.2 由於多種原因（例如，其他介入措施，自然發育變化等），您孩子的能力水平可能會發生變化（上升或下降）。您認為孩子的實用性技能變化（如果有的話）在多大程度上是跟參與此服務有關？

☐	☐	☐	☐	☐	☐
1	2	3	4	5	沒有變化
根本沒有		中等地		非常地	

H2.3 請回答最符合您孩子進度的陳述：

A) 自此服務開始以來，您如何評價您的孩子在社交和遊戲技能方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

B) 自此服務開始以來，您如何評價您的孩子在學業技能方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

C) 自此服務開始以來，您如何評價您的孩子在溝通技巧方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

D) 自此服務開始以來，您如何評價您的孩子在自理技能方面的進步？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

E) 自此服務開始以來，您如何評價您的孩子在行為問題方面的改善？

☐	☐	☐	☐	☐
1	2	3	4	5
變差了	沒有提高	少量提高	有些提高	大量提高

H3 請添加您對本次調查的任何其他意見，或者有關您的自閉症兒童所接受之相關服務的寶貴意見。

謝謝您完成此問卷！想在此詢問您是否有意願參與下一階段的研究？我們想要瞭解台灣家長對於 ABA 服務的經驗及所遇到之困難。此研究將由團隊成員以半結構性的訪談組成，約莫耗時一小時，以您方便的時間為主。訪談結束後，我們將給予折合台幣 150 元的禮卷。

☐ 是的，我有興趣參與。我想知道更多相關資訊。
請填入您的名字及聯絡資訊（電子信箱/電話），我們團隊成員將與您聯繫並給予相關資訊。

姓名 _____

電子信箱 _____

電話號碼 _____

☐ 不了，我沒有興趣參與

非常感謝您抽出寶貴的時間來完成這份調查問卷！

我們將贈與您折合台幣 150 元的禮卷。請勾選是否想要拿到禮卷，若勾選是，禮卷將在兩個星期之內寄出。

請填寫下列內容。您的問卷回覆將不會呈現您的姓名及其他資料。

姓名：_____

電話號碼：_____

電子郵件：_____

Appendix C

Parent interview guide

General background questions

1. Tell me about yourself and your child

General autism services

1. What has your experience been obtaining services for your child? (PROBE: what are things you consider? Where did you hear about these services?)
2. What are services your child has received? What has been the most helpful? What has not been helpful?
3. What are some services your child has not received, but would be helpful?

ABA services

1. How did you first hear about ABA? (Probe: what did you think about it? Has that changed?)
2. Can you tell me what it was like to obtain ABA services?
3. What has your experience been with ABA services? Therapists? Centres? (Probe: *What was positive about the experience? What was negative about the experience?*)
4. What is important to you in selecting ABA services for your child?
5. What has been difficult about finding ABA services for your child?
6. Would you recommend ABA to a child with similar needs?

Suggestions for ABA Centres in Taiwan

1. What would be helpful for ABA service providers to do for families with children with ASD?

Professional interview guide

General background questions

1. Tell me about yourself and how you became involved with ABA (Probe: how many years in ABA, how many years working in Taiwan, if they talk about BCBA, ask them why they got it)

ABA services

2. How did you first hear about ABA? (Probe: what did you think about it? Has that changed?)
3. What has your experience been with ABA services? Other therapists? Centres? (Probe: *What was positive about the experience? What was negative about the experience?*)
4. What are some barriers for parents obtaining ABA?
5. What are some barriers for professionals in the field of ABA?
6. What are some difficulties that ABA centres face in Taiwan?