The feasibility, acceptability, and efficacy of a manualized training program to teach ABA strategies to university students in Eastern Kazakhstan.

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Declaration

I, Erin Moran, confirm that, apart from where explicitly stated below, all the work presented in this thesis is entirely my own.

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Abstract

Individuals with autism and their families often face challenges, including stigma, discrimination, and unequal access to education are common. Interventions based on the principles of applied behavior analysis (ABA) show the most promise for improving outcomes for autistic individuals, however, these services are often inaccessible to families living outside the United States due to a lack of qualified professionals and a lack of training programs for local professionals. This is the case in Eastern Kazakhstan, where not only are there are no formally qualified professionals in ABA, there is an overall lack of trained teachers and psychologists to work with children with autism. Little information regarding autism diagnosis, provisions, and parental support in Kazakhstan exists. This thesis explored the experiences of mothers of children with autism and other developmental disabilities in Kazakhstan. 12 mothers participated in semi-structured interviews and four themes emerged and are examined.

The main study in this thesis sought to address the lack of training programs. Due to the parent reported 'poor attitudes' of in-service teachers, pre-service university students were targeted. A manualized training programme was developed to teach university students to implement ABA strategies. Due to the lack of trained professionals, mothers of children with autism delivered the training. The training manuals were scripted and structured based on behavioural skills training. 10 training sessions were delivered to 21 university students over a two-week period. Pre- and post-training competency assessments showed that the training was effective in teaching the university students to perform ABA strategies in role-play scenarios. A follow-up study was conducted at a local centre to determine of the skills taught in the training programme would generalize to use with children with autism. While the follow-up revealed that the short-term training programme was successful in teaching ABA skills, the participants made errors when implementing them in applied settings

highlighting the need for highly trained professionals to oversee ABA services. Implications for short-term and international training programmes are discussed.

Impact Statement

This thesis may have an impact both within and outside of academia. Individually, the participants in the study all learned new skills that are likely to be used to serve children with autism in Eastern Kazakhstan. The mothers left with a greater sense of empowerment and many reported the ability to better communicate with their children. Many of the university students reported a desire to learn more and work with children with autism. In Kazakhstan, news of the study brought attention to topic and raised autism awareness. The study also garnered attention from other groups throughout Kazakhstan and have led to new connections. I have been invited back to the local university to provide further training to university staff and students. Researchers and professors in Russia, Saudi Arabia, Norway, and the United States have shown interest in replicating the research and in using the manuals. The training program could be adapted to any country's cultural context and used to better prepare individuals to teach children with autism.

The results from this thesis could be used in future advocacy efforts in Kazakhstan. The mothers of children with autism have be extremely active in lobbying for increased services for their children, but often have been told that "We don't have any evidence that XYZ treatment will work here in Kazakhstan." The main study provides evidence that people in Kazakhstan can successfully be trained to implement the evidence-based practices. There is also very little evidence of the current problems faced by children with autism and their parents. This thesis provides a detailed account of the current situation in Kazakhstan and the mother's experiencing of obtaining a diagnosis and seeking treatment. This evidence can be used to demonstrate the problems and advocate for changes.

Inside of academia, this thesis contributes to future scholarship in areas of behavioural skills training and autism in the context of Kazakhstan. The interviews are only the second paper specifically investigated autism in Kazakhstan from the parent's perspective and the

only paper to do so in a rural area. The thesis also contains the only field report describing the current service delivery systems in Eastern Kazakhstan. These chapters can be drawn upon to develop future research projects concerning autism in Kazakhstan. This thesis also includes the largest behavioural skills training study and the only one conducted outside of the United States.

Dissemination

Publications

Data from chapter four included in:

Moran, E., Mandy, W., Crane, L., & Allen, J. L. *Trapped in a room with no doors: The experiences of mothers of children with autism in Kazakhstan.* Submitted.

Data from chapter seven included in:

Moran, E., Mandy, W., & Allen, J. L. *Parent-led behavioural skills training programme to teach university students ABA strategies in Kazakhstan.* Manuscript in preparation.

Data from chapter eight included in:

Moran, E., Mandy, W., & Allen, J. L. *Improving special education tutor's performance skills using a manualized behavioral skills training program in Kazakhstan.* Manuscript in preparation.

Conference presentation

Data from chapter seven presented at:

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Data from chapters seven and eight presented at:

Moran, E. *Manualized behavioural skills training program to teach ABA strategies in Kazakhstan*. North Carolina Association for Behavior Analysis 30th Annual Conference, Winston- Salem, NC, February 2019.

Data from chapters seven and eight presented at:

Moran, E., & Allen, J. A. *Behavioural Skills training in Kazakhstan.* 9th Conference of the European Association for Behaviour Analysis, Wurzburg, Germany, September 2018

Study design and planning presented at:

Moran, E. *Inclusive education in Kazakhstan: Utilizing parental involvement to make the dream become a reality,* V Annual Research Forum for Central Asia, London, UK, March 2018.

Conference Poster presentations

Data from chapter four presented at:

Moran, E., Allen, J., & Mandy, W. *The experiences of mothers of children with autism in Kazakhstan: A pilot study.* Poster presented at UCL Institute of Education Poster Conference, London, UK, March 2018.

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Reflections from field study described in chapter five presented at:

Firm and flexible: Lessons learned from conducting international research. Departmental Doctoral Seminar Series, UCL IOE, London, UK, December 2018.

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Research design and planning presented at:

Teaching university students Applied Behaviour Analysis strategies for children with autism in Kazakhstan: Utilizing parental involvement, Shine Lab, UCL Institute of Education, January 2018.

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List of Abbreviations

ABA	Applied Behaviour Analysis
ABC Data	Antecedent, Behaviour, Consequence Data Collection
ADI-R™	Autism Diagnostic Interview-Revised
ADOS™	Autism Diagnostic Observation Schedule
AUTISM	Autism Spectrum Disorder
BACB ®	Behavior Analysis Certification Board®.
BCBA ®	Board Certified Behaviour Analyst®.
BST	Behavioural Skills Training
CAM	Complementary and Alternative Medicine
DR	Differential Reinforcement
DTT	Discrete Trial Training
EBP	Evidence-Based Practice
EIBI	Early Intensive Behaviour Interventions
FC	Facilitate Communication
FCT	Functional Communication Training
FES	Family Empowerment Scale
IT	Incidental Teaching
MSWO	Multiple Stimulus Without Replacement Preference Assessment
PDD	Pervasive Developmental Disorder
PEAK	Promoting the Emergence of Advanced Knowledge
PECS®	Picture Exchange Communication System

PMPC	Psycho-medical and Pedagogical Commission
RIRD	Response Interruption Re-direction
RBT®	Registered Behaviour Technician ®.
RCT	Randomized Control Trial
SACIE-R	Sentiments, Attitudes, and Concerns about Inclusive Education Revised (SACIE-R) Scale
VCS	Verified Course Sequence

1. Introduction

1.1 Autism Spectrum Disorder

Autism Spectrum Disorder is a complex neurodevelopmental disorder that affects communication, language and behaviour (American Psychiatric Association, 2013). Autism is a lifelong disorder with signs and symptoms emerging in early childhood. The core symptoms include social communication challenges (eye contact, spoken language, facial expressions, recognizing emotions, etc.) and restricted and repetitive behavior. The cause of autism is currently unknown, but evidence suggests that there are many factors that make it more likely for a child to have autism, including environmental and genetic factors. Children with autism often have co-occurring mental health disorders, intellectual disability, and physical health problems (Mannion & Leader, 2013). There is currently no cure for autism. However, early intervention can produce improvements in cognitive abilities, language, and adaptive behaviour (Eikeseth, Smith, Jahr, & Eldevik, 2002). Long-term outcomes vary, with research suggesting low levels of independent living (Howlin, 2000) and low levels of employment (Taylor, Henninger, & Mailick, 2015). However, other research suggests that those with average or above-average IQ are more likely to have favourable outcomes in terms of education, career, and independence (Cederlund Hagberg, Billstedt, Gillberg, & Gillberg, 2008).

1.2 Autism in Kazakhstan

Kazakhstan is the world's ninth largest country and the largest landlocked country (World Bank, 2016). It is approximately 11 times bigger than the UK. Kazakhstan has a population of 16.35 million, making it one of the most sparsely populated countries in the world (World Bank, 2016). The country is officially a democratic, constitutional republic that gained its independence from the Soviet Union in 1991. Since 1991, Nursultan Nazarbayev

has served as the president of Kazakhstan. Mr. Nazarbayev has run for office mostly unopposed and is widely supported by most Kazakhs. However, others claim the president holds too much power and suppresses political opposition (Isaacs, 2010). Nonetheless, Kazakhstan has the largest and strongest performing economy in the Central Asian region and many attribute its economic success to his leadership. Despite its relative wealth, Kazakhstan spends comparatively little on education (UNDP, 2013). Several international reports have cited that Kazakhstan needs an overhaul of their education system, with updated teacher training, accessible facilities, and an increase in teacher pay (Organization for Economic Cooperation and Development, 2009; UNDP, 2013).

Currently, very little is known about the experience of receiving an autism diagnosis in Kazakhstan. The information available indicates that there is an overall lack of trained professionals and appropriate services available for children with autism (An, Chan, & Botagoz, 2018). Additionally, the diagnostic and educational placement process is very long and stressful for parents (Markova & Sultanalieva, 2013). In order to receive an education, children with autism must report to a special Committee which decides if the child is 'educable' or not (Markova & Sultanalieva, 2013). After this point, children can be directed towards a special education school, a rehabilitation clinic with no educational curriculum, remedial and limited home schooling (typically a one to two-hour home visit from a teacher one to three times a week) or denied access to any schooling. Even if a child is placed in a school, their placement is not secure; schools have the ability to expel a student at any time. Parents have reported this process to be extremely frustrating (An et al., 2018). There is an overall lack of qualified professionals to autistic children make meaningful improvements in their language, social skills, and daily living skills and scarce training opportunities to develop the skills necessary to work with children with autism.

1.3 Research Aims and Questions

This thesis employs a mixed-methods approach to accomplish the following aims:

(1) Perform semi-structured interviews with mothers of children with autism in rural cities to gain insights into their perspectives on obtaining a diagnosis, finding an educational placement, and experiences stigma in the community. Explore the ways in which their experiences are the same or different compared to families who live in the two major cities, Almaty and Nur-Sultan.

(2) Produce a reflective report, based on personal experiences in Kazakhstan, to provide context and discuss the current diagnostic process, professional training, and private services available in Eastern Kazakhstan.

(3) Develop a training manual, based on current best practices and sensitive to the cultural context of Kazakhstan, to train parents and university students to work with children with autism in schools using a train-the-trainer model approach

(4) Assess and evaluate the feasibility, acceptability, and efficacy of the training programme

Aim 4 will address the following research questions:

RQ 1: Can this course teach parents and students to accurately implement ABA strategies?

RQ 2: Is this training course feasible and acceptable to parents, university students, and professionals?

RQ 3: Can this course increase students and parents' knowledge of autism and ABA?

RQ 4: Can this course change student attitudes towards inclusive education and autism?

RQ 5: Can this course increase parental empowerment?

1.4 Chapter Overview

Following the introductory chapter, Chapter 2 provides an overview of the diagnosis, prognosis, and treatment for autism. Chapter 2 discusses historical and contemporary uses, issues, and applications of ABA. The chapter investigates evidence-based practice in relation to autism interventions and ABA. The chapter also includes an extensive review of behavioural skills training, an evidence-based approach to training individuals to implement interventions based on ABA strategies. The chapter concludes with an overview of parental involvement in the training of teachers and professionals when working with children with autism.

Chapter 3 includes an in-depth account of disability services and treatment during the Soviet era. The chapter discusses how the Soviet legacy is continuing to influence modern day treatment of children with disabilities in the post-Soviet country of Kazakhstan. The current diagnosis, treatment, and education of autistic children in Kazakhstan is examined. The role of NGOs and parent advocacy groups in the promotion of autism awareness is explored. Current teacher and professional training programs are also discussed.

Following the literature review chapters, each subsequent chapter is linked directly to a research aim. Chapter 4 addresses Aim 1 and presents a qualitative study exploring the experiences of mothers of children with autism and related disorders in Kazakhstan. Due to the lack of information regarding diagnosis, treatment, and educational provisions, 12 semi-structured interviews were performed to provide a detailed account of the mothers of autistic children. Four themes have been identified and are discussed.

A reflective report is presented in Chapter 5 that addresses Aim 2. This account reports observations made during the fieldwork trips to Kazakhstan. Field notes, informal interviews, and participant observations were made at the university training programme site, the diagnostic centre, and centre providing services for young children with autism are

reported and discussed. Recommendations for areas of development and improvement are given.

Chapter 6 accounts for the conceptualization and development of the training manuals for the main study, fulfilling the objectives in Aim 3. Criteria for the selection of the targeted skills is outlined along with a description of each skill. The design of the manuals based on behavioural skills training is explained. Photographs and examples for the student and instructor manuals are included in the description of each manual.

The main study is discussed in Chapter 7, which explores the research questions included in Aim 4. This chapter provides a detailed account of the methods and results of the investigation of the effectiveness of the training program in Kazakhstan. The chapter also includes a description of the implementation of the project.

Chapter 8 describes a brief follow up study, providing additional insights to the research questions in Aim 4. The purpose of the follow up study is to expand on the findings of the main study and address some its limitations. In this study, the training was delivered to a group of seven in-service tutors who had minimal training in ABA. The training was co-delivered by the researcher and a mother of a child with autism. The skills taught in the training program were assessed in-vivo to determine if skills taught in a role-play training would generalize to use in situ.

A discussion of the results from the entire thesis are presented in Chapter 9. This chapter will provide an overview of the challenges faced by those in Kazakhstan, obstacles to implementing training programmes, and future directions for research regarding autism training and international development.

1.5 Personal Background

I am an American researcher with no ties to Kazakhstan prior to 2015. In 2015, I made my first trip to Kazakhstan. At that time, I was living in Asia and completing my

Masters programme in Applied Behaviour Analysis and accruing my fieldwork hours for certification. I found a post online from a group of mothers of children with autism in Kazakhstan that were seeking an ABA tutor to come and help their children. At the time, I did not know much about autism in post-Soviet societies, but I assumed these mothers faced a great deal of stigma and discrimination and felt compelled to work with them. Instead of going to directly work with their children, I instead designed and delivered a two-month parent training programme. During this programme, basic principles of applied behavior analysis were conveyed, psychoeducation was provided to explain what autism is, its cause, and discuss various treatment options. While there, the mothers explained their situations to me and I left Kazakhstan with much more questions than I originally went there with.

After this trip, I obtained my certifications as a Board Certified Behavior Analyst and worked in the USA delivering home-based services. I later developed my research proposal for this thesis based on my experience in Kazakhstan in 2015. Many of the mothers I met in 2015 participated in my research in one way or another. The group that sponsored my first visit had since established a new centre for children with disabilities which served as one of the main sites of my research studies.

2. Autism Spectrum Disorder and Applied Behaviour Analysis

2.1 PART 1: Autism Spectrum Disorder

Autism Spectrum Disorder (henceforth autism) is a neurological disorder that persists across an individual's lifetime. It is characterized by impairments in communication, social interactions, and repetitive behaviours (American Psychiatric Association, 2013). The Center for Disease Control and Prevention (CDC) estimates that one in 54 children have autism (CDC, 2020). The cause of autism is currently unknown, but evidence suggests that there are many factors that make it more likely for a child to have autism, including environmental and genetic factors (Mandy & Lai, 2016). Children with autism often have co-occurring disorders, including anxiety, depression, Attention Deficit Hyperactive Disorder, Bipolar Disorder, Down Syndrome, and Obsessive-Compulsive Disorder (Siminoff et al., 2008). Additionally, common physical health problems include gastrointestinal symptoms, immune disorders, seizure and epilepsy, sleep problems and feeding disorders (Mannion & Leader, 2013). Approximately 50% of children with autism also have an intellectual disability (Charman, Pickles, Simonoff, & Sanders, 2011).

In recent years, the terminology surrounding autism has received attention. Person-first language ('person with autism') is recommended by the American Psychological Association's (APA, 2018). However, there is much disagreement and many prefer identity-first language ('autistic person'). One study surveyed 3,470 UK residents, including autistic people, parents of children with autism, and their support networks (Kenny et al., 2016). The results indicated there are a wide variety of terms used to describe autism spectrum disorders with some differences amongst groups. Autistic adults, their family members, and parents were more likes to endorse the term identify-first language, while professionals were more likely to endorse person-first language. To represent the various preferences for language, person-first and identity-first language will be used interchangeably in this thesis.

2.1.1 Diagnosis.

Autism is a behaviourally diagnosed disorder that typically involves a multi-disciplinary team completing structured observations, parent interviews, and a review of medical history to determine the diagnosis (Volkmar et al., 2014). The 'gold standard' assessment tools for diagnosing autism are the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS; Falkner, Anderson, Falkner, & Horlin, 2013; Ozonoff, Goodlin-Jones, Solomon, 2005). These tools have excellent interrater reliability and can be administered and scored in 90-180 minutes and 30-60 minutes, respectively (Payakachat, Tilford, Kovacs, & Kuhlthau, 2012). However, clinicians must have extensive training and expertise to utilize these tools (Zander et al., 2016).

Although autism can be reliably diagnosed at 24 months (Lord et al., 2006; Moore & Goodson, 2003), one study examining age of diagnosis in 12 countries found the average age of diagnosis ranged between 38-120 months (Daniels & Mandell, 2014). Delayed diagnosis is related to a combination of clinical, family, community and socioeconomic factors (Daniels & Mandell, 2014). For example, some families may delay a diagnosis for fear of stigma or negative connotations that may with a diagnosis (Daniels & Mandell, 2014). However, others may be delayed due to a lack of service providers or extended waitlists (Keenan et al., 2010). Early diagnosis is critical, as early interventions have been linked to improved outcomes (Dawson et al., 2010; Eikeseth, Smith, Jahr, & Eldevik, 2002).

2.1.2 Prognosis.

Autism is commonly viewed as lifelong disorder, with symptoms of autism commonly emerging in early childhood (APA, 2013). Long-term outcomes vary, with research suggesting that people with autism are less likely to live independently (Howlin, 2000) and reduced employment (Taylor, Henninger, & Mailick, 2015). Other research suggests that those with average or above-average IQ are more likely to have favourable

outcomes in terms of education, career, and independent living (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008).

Though many autistic individuals live independent lives and show strengths in many areas, such as increased attention while performing a task (Remington & Fairnie, 2018), the mental and physical health problems associated with autism often comes at a great emotional and financial cost to people with autism and their families. Parents of children with autism also report significantly greater levels of stress in comparison to parents of typically developing children or children with other developmental disabilities (Hayes & Watson, 2013). The lifelong cost of services, support and lost productivity for an individual with autism with an intellectual disability is approximately £1.23 million and £800,000 for an individual without an intellectual disability (Knapp, Romeo, & Beecham, 2009). World-wide, people with autism and their families are often met with discrimination and stigma, in addition to unequal access to education, healthcare and community activities (Johnson & Levine, 2014). People with autism are a vulnerable group and are at increased risk for violence, injury, and abuse compared to the norm (Nowak, 2015). Healthcare providers, educators and community members often have an inadequate or inaccurate knowledge of autism (Obeid et al., 2015). This may lead children with autism to receive poor quality health, education and social services or be excluded from community events.

There is currently no cure for autism. In fact, even the notion of a 'cure' is controversial, with many viewing autism as an integral part of their identity (Barnes & McCabe, 2011). Some autistic adults associated with the neurodiversity movement (see Section 2.2.2) believe that autism is a difference, not a disorder and is a natural variation among humans (Jaarsma & Welin, 2012). Many autistic advocates in this movement oppose the development of pre-natal screening, rehabilitative therapy (i.e. behavioural interventions), and 'cures' as they are seen as attempts to eliminate rather than improve the lives of autistic

individuals (Runswick-Cole, 2013; Solomon, 2012). These stances are at odds with many parents of autistic children. The parents believe that the autistic self-advocates, who typically have higher cognitive function and language abilities, do not represent the full spectrum of individuals complex needs and co-occurring cognitive and learning delays (Jaarsma & Welin, 2012). Without interventions, some argue that their children would not develop the necessary language and communication skills to advocate for themselves (Baker, 2011; Stagliano, 2010). These groups are often at odds and is currently unresolved.

Despite the ongoing debates, research has shown that early intervention can lead to increases in cognitive abilities, language, and adaptive behaviour, improving long-term outcomes (Eikeseth, Smith, Jahr, & Eldevik, 2002). One retrospective study found that some individuals with an early diagnosis of autism later did not meet the diagnostic criteria for autism. These individuals were found to receive earlier, more intensive services and more services based on the principles of ABA than those who kept their autism diagnosis (Orinstein et al., 2014). This study suggests that early, intensive interventions based on the principles of ABA may lead to optimal outcomes and normal cognitive functioning.

2.1.3 Common interventions.

As autism awareness and prevalence rates continue to rise, so does the demand for treatment. In the United States, the 2017 autism treatment market was estimated to be $1.87 billion and is expected to rise to $2.23 billion in 2022 (Marketdata Enterprise Inc, 2018). With this expanding market, there are a growing number of treatments available to address the distress and impairments associated with autism. One study found are over 100 interventions for the core symptoms of autism (Green et al., 2006). As diagnosis generally occurs in early childhood, parents are primarily responsible for selecting their child's treatment as the children are not able to do so themselves. Parents report finding the search and decision-making process around treatment stressful, largely due to receiving conflicting

information and advice from professionals (Green, 2007; Mandell, Novak, & Zubritsky, 2005). Parents may or may not have the skills to critically assess each intervention to determine the strength of its evidence base. Therefore, many parents may rely on the media and suggestions from other parents when making their treatment selection (Mackintosh, Myers, & Goin-Kochel, 2005; Miller, Schreck, Mulick, & Butter, 2012). This may be problematic as the validity of the information from websites and other sources can be questionable. Given the wide range of treatments available and the variability in the quality of evidence to support these treatments, it is critical to understand research findings on the efficacy and effectiveness for common approaches. This section describes a selection of common autism interventions that either have limited support or have been proven to be harmful; yet are still practiced today.

Harmful interventions. Chelation, holding therapy, and facilitated communication have proven to be some of the most dangerous interventions. Both chelation and holding therapy have resulted in deaths, while facilitated communication has resulted in damaging court cases. Chelation is the process of eliminating mercury and heavy metals from the body. It gained popularity in the early 2000s despite a lack of supporting evidence (Ng, Chan, Soo, & Lee, 2007). A clinical study found no statistically significant behavioural benefit from this therapy (Adams et al., 2009). In 2006 the Centre for Disease Control (CDC) reported that during the period between 2003 and 2005 three deaths associated with chelation, including one of a young boy with autism. Given the high risk involved in this therapy and the lack of evidence to support it, it is recommended by the National Institute for Health and Care Excellence that this treatment not be used.

Another two deaths were attributed to holding therapy in 2002 (Boris, 2003). Holding therapy is the use of forced restraint to promote attachment between the parent and child and was first proposed as a cure for autism in the 1970s (Zaslow & Menta, 1975). Holding

therapy consists of parents or therapists forcing holds with the child until the child stops resisting or until a fixed amount of time has passed. The adult often waits until the child makes eye contact and then provides affection to the child. The intense holds are meant to mend the broken bond between parent and child to promote normal development. During this therapy, parents were told to expect bruises, screaming, and crying (Zaslow & Menta, 1975). Some researchers stated that the physical and emotional restraint and intrusiveness of this therapy meet the abuse criteria of the National Incidence Study of Child Neglect and Abuse (Mercer, 2013; Sedlak, Schultz, & Cook, 2005). There are currently no studies of a high quality to provide evidence to suggest this is an effective treatment. Of the three total research studies investigating holding therapy, one was a case study of a single child and the other two were case series published by the creator of holding therapy (Lindt, 1988; Welch, 1989; Welch & Chaput, 1988). There are no known ongoing studies investigating this treatment. Despite the lack of evidence and reports of harmful consequences, holding therapy was endorsed by a 2010 article published in the British Journal of Social Work and is still used today (Mercer, 2013; Sudbery, Shardlow, Huntington, 2010).

Facilitated communication (FC) brought a different set of harmful consequences. FC is an intervention for individuals with communication difficulties where a facilitator assists with typing or producing a message via pointing (Biklen, Morton, Gold, Berrigan, & Swaminathan, 1992). In other words, a facilitator assists an individual in composing a written message. FC was initially viewed as a miracle intervention that unlocked the inner voices of autistic children. However, messages of alleged abuse began to be produced by children who communicated through FC. In these messages, the children accused their parents or caregivers of sexual abuse. There were at least five dozen cases uncorroborated accusations of sexual abuse by caregivers and parents of the individual with disabilities (Jacobson, Foxx, & Mulick, 2016; Margolin, 1994). As a result, children were removed from their homes and

some parents were sent to prison (Goreman, 1998). Scientific testing was then completed and determined that the authorship of all of the accusations belonged to the facilitator, not the individual with a disability (Bomba, O'Donnell, Markowitz, & Holmes, 1996; Lilenfeld, Marshall, Todd, & Shane, 2014; Moore, Donovan, & Hudson, 1993; Salovita, Lepannen, & Ojalammi, 2014; Shane & Kearns, 1994; Smith, Haas, & Belcher, 1994; Wheeler, Jacobson, Paglieri, & Schwartz, 1993). A 2014 systematic review echoed these finding and claimed that authorship of messages from FC are unequivocally those of the facilitators, not the individuals with disabilities (Schlosser et al., 2014). The facilitators, whether consciously or unconsciously, were responsible for the composition of the messages, which included the accusations of abuse. The court cases were settled, and individuals were released or freed from charges, however, there is likely lasting damage to the reputation of those accused (Goreman, 1998; Lilienfeld et al., 2014).

Unsupported interventions. Most pseudoscientific therapies do not have such documented harmful effects. However, the use of unsupported and ineffective treatments drains financial resources, can be detrimental to child and family morale and can waste time which could otherwise be spent on supported interventions. The appeal of pseudo-scientific therapies may lie in the relative ease of implementation in comparison to behavioural interventions that are often time consuming and expensive (see below for description of behavioural interventions; Smith, 2016). As there is currently no intervention that can address the wide range of difficulties people with autism may face, families may select several different interventions to address the various problems (sleeping difficulties, feeding difficulties, communication delays, etc.). For example, weighted blankets may be used to specifically address relaxation and sleep problems (Olson & Moulton, 2004). However, there is limited empirical evidence to support their widespread use. A randomized, placebo-controlled crossover design of 67 children found no objective or subjective benefits of sleep

using a weighted blanket (Gringas et al., 2014). Despite no measured improvements in sleep, parents and children reported preferring the weighted blankets to the placebo blankets and no adverse effects were found. This provides just one example of a therapy that, while not harmful, has no tangible benefit and may represent a waste of resources.

Sensory integration therapy (SIT) is also commonly used to treat children with autism. The purpose of SIT is to help children with poor sensory integrations better receive and process sensory inputs. Individuals with poor sensory processing may have difficulty controlling their bodies and coping with environmental events (noises, lights, etc.). SIT seeks to balance out sensory processing difficulties by adding in specific activities as part of a sensory diet to help the child regulate better. These activities may include massage, joint compression, brushing, swinging, jumping, etc. SIT is often implemented by occupational therapists and physiotherapists. There is a small amount of research investigating SIT and results are mixed. Several reviews have analysed what few studies exist and did not find strong evidence to support SIT for its treatment for individuals with autism (Dawson & Watling, 2000; Smith, Mruzek, & Mozingo, 2014). More high-quality research studies would need to be performed to determine the efficacy of this treatment.

Complementary and alternative medicine (CAM) are also widely used despite a weak evidence base. CAM practices include medicinal practices and products that are not part of conventional medicine. CAM practices are often in one of five categories: whole medicine systems (naturopathy, homeopathy, traditional Chinese medicine, etc.), energy medicines, manipulative and body-based practices (chiropractic, massage, cranial osteopathy, etc.), mind body medicine (meditation, martial arts, acupuncture, yoga, etc.), and natural products (vitamins, minerals, etc.). One study of American families of autistic children found that 74% of families (n=112) reported using a CAM practice for their child with autism (Hanson et al, 2007). Results suggest that parents of children with more severe symptoms were more likely

to use CAM. Parents with higher educational attainment were also more likely to use a CAM. The high rate of CAM use may be attributed to family's preferences for "natural" remedies and a dissatisfaction with traditional treatments and their failure to address all of the associated symptoms of autism and common co-occurring difficulties (Astin, 1998). Despite their widespread use, there is little evidence supporting their effectiveness. Due to the wide range and variety of CAM practices, there is currently not enough high-quality research investigating the individual practices to evaluate their scientific merit. Most research needs to be completed in this area to evaluate their effectiveness.

Pharmacological interventions are also commonly used for children and adults with autism. One of the most widely studied drugs to treat autism is secretin. In the late 1990s secretin showed the potential to 'cure' autism (Horvath et al, 1998). Significant attention and financial resources were spent on testing its effectiveness (Esch & Carr, 2004). However, a review of 16 clinical trials, involving a total of 900 autistic children, found no supporting evidence for the use of secretin (Williams, Wray, & Wheeler, 2012). Risperidone is another drug that has been studied for its use in decreasing problem behaviour (aggression, self-injury, and repetitive behaviour). A meta-analysis of the effects of risperidone showed a decrease in problematic behaviour, supporting its use for children with autism (Sharma & Shaw, 2012). However, all studies also showed significant weight gain in the children taking the drug. Furthermore, while risperidone was found to reduce problematic behaviour, it was unable to address the core symptoms of autism.

Many psychotropic drugs are used to treat anxiety and depression for adults with autism, but these drugs are prescribed to children 'off label' (Devulapalli, & Nasrallah, 2009). In other words, the prescribed drug has been approved for the treatment of a mental or physical disorder other than autism (epilepsy, high blood pressure, depression, anxiety, etc.), yet is being used to treat individuals with autism for their autistic symptoms. Rates of use of

psychotropic drugs among children with autism are high and vary greatly based on the geographical location. One study in the United Kingdom found that approximately one in three autistic individuals are prescribed psychotropic medication based on medical records of 40,000 individuals (Houghton, Lui, & Bolognani, 2018). In the United States, one study found that nearly half (48.5%) of autistic children aged 1-17 received psychotropic medications during a one year time period (Madden et al., 2017). Both studies noted that the high rates of use of these drugs is worrisome, given the lack of research to support their effectiveness in treating autism symptoms and the unknown long-term effects of these medications.

Developmental-based or relationship-based interventions have recently gained popularity. These interventions target the core symptoms of autism (social and relational deficits), not the overt behaviours (specific skill acquisitions or decreases in maladaptive behaviours) and focus on the relationship between the caregiver and the child (Ingersoll, Dvortesak, Whalen, Sikora, 2005). The Developmental, Individual Differences, Relationship-based model (DIR/Floortime ^{TM}) is one of the most widely used relationship-based interventions; yet there is very little evidence for its effectiveness in treating autism symptoms. DIR/Floortime is a comprehensive intervention designed to target educational, social-emotional, mental health, and developmental challenges. This intervention seeks to help children reach developmental milestones through playful interactions with adults. DIR/Floortime is designed to be implemented by the parents. The parents are encouraged to follow the child's lead and let their interests guide the session. A number of organizations and independent researchers have evaluated the existing literature on DIR/Floortime ^{TM} and found little to no evidence supporting its use (Autism Partnership Program, 2011: Maine Department of Health and Human Services, 2009; Odom, Boyd, Hall, & Hume, 2012). A 2015 review found several limitations in the DIR/Floortime literature; the studies failed to

include a comparable control or comparison group, with participants in the DIR/Floortime group receiving a larger number of treatment hours (Mercer, 2015; Solomon et al., 2014). The study found that there has not been a systematic comparison of DIR.Floor-time to any other intervention. Additionally, the review noted that there have been no independent replications of DIR/Floortime. Despite the lack of evidence, DIR/Floortime remains a popular intervention.

The interventions mentioned in this section provide only a few examples of the tremendous number of differing autism treatments and therapies. This brief examination of the various types of treatments demonstrates the potential harm caused by the use of unsupported treatments. Future research should further examine parental decision-making processes around treatment decisions and what supports could be provided to help parents make informed decisions.

2.2 PART 2: Applied Behaviour Analysis

Behavioural interventions have a stronger evidence base than the treatments described in Section 2.1 (Wong et al., 2013). These behavioural interventions are derived from the field of Applied Behaviour Analysis (ABA). ABA is a science focused on understanding and improving human behaviour (Cooper, Heron, & Heward, 2007). It is an applied science that coincides with two other branches of behaviours analysis; *behaviourism*, the philosophy of the science of human behaviour and the *Experimental Analysis of Behaviour*, the basic research that defines the underlining principles of ABA.

Behaviourism emerged in the late 19th and early 20th centuries and was pioneered by Edward Thorndike, John B. Watson, Ivan Pavlov, and B. F. Skinner. Watson was responsible for establishing methodological behaviourism, an approach that did not consider internal events (thoughts and feelings) as observable and measurable behaviours. Skinner went on to develop radical behaviourism, which included internal events into the scope of behaviourism.

The application of Skinner's radical behaviourism to everyday behaviours and events is ABA. The purpose of ABA is to apply procedures, based on the principles of learning, to improve socially significant behaviours. ABA has been successfully used to address environmental and sustainability issues, business and organization management, speech and language pathology, addiction, gambling, gerontology, animal training, health and fitness, and sports performance (Ferguson & Rosales-Ruiz, 2001; Dickinson, 2000; Fisher, Harsin, & Hadden, 2000; Lehman & Geller, 2004; Marley, & Jacobs, 2003; Martin, Thompson, & Regehr, 2004; Reynolds, Dallery, Shroff, Patak & Leraas, 2008; VanWormer, 2004). Although the principles of ABA have been applied to many fields, it is most widely used and known for its role in the treatment for autism, intellectual, and developmental disabilities.

2.2.1 A brief history of applied behaviour analysis.

John B. Watson is often identified as one of the pioneers of early behaviourism. In 1913 he stated that "psychology as the behaviourist views it is purely an objective experimental branch of natural science" (p. 158). He explained that introspection played no part in the evaluation or interpretation of human behaviour. Instead, he argued that the study of behaviour should focus on the observation of environmental stimuli (S) and the responses (R) they evoke. This was coined as the stimulus-response (S-R) psychology. While at the time he was unable to use this model to explain all human behaviour, it paved the way for future researchers to view human behaviour in a unique manner.

In his 1938 article "The Operational Analysis of Psychological Terms" Skinner founded radical behaviourism. This approach considered internal events as behaviours that are subject to the same contingencies as outward behaviours. Went on to establish the Experimental Analysis of Behaviour (EAB), which identified both respondent and operant behaviour. *Respondent behaviour* is derived from Pavlov's reflexive behaviour, where responses are "brought out" by the stimuli that immediately precede them. *Operant*

behaviour are behaviours that have been learned based on prior experiences and are influenced by the stimulus that follows the behaviour. A new three-term contingency, S-R-S model was identified. Laboratory research was conducted on both animals to establish the basic principles of behaviour.

During the 1940s and early 1960s the research performed on rats and pigeons began to be conducted on human participants (Rutherford, 2009). Fuller (1949) published the first human study using operant conditioning to successfully treat an 18-year-old male with profound developmental disabilities. The Journal of Applied Behavior Analysis (JABA) was established in 1968. In that same year Baer, Wolf, and Risley published the seminal articles "Some Current Dimensions in Applied Behavior Analysis". This article detailed a framework for taking the laboratory and applying it to use with humans. The authors aimed to make a distinction between experimental and applied research and heavily stressed the need to use the science to address socially-significant behaviours. The article outlines seven dimensions for conducting applied behaviour analysis research and practice: generalization, effective, technological, applied, conceptually systematic, analytic, and behavioural as shown in Table 2.1.

Table 2.1

Seven Dimensions of Applied Behaviour Analysis Research as Defined by Baer, Wolf, and Reisley (1968)

Dimension	Description
Generalization	All skills or behaviours taught during the intervention should be able to occur in environments or behaviours other than where they were discretely taught. If an individual is taught to tie their shoes at school, they should be able to tie their shoes at home.
Effective	Interventions improve behaviours that produce practical results for the participant.
Technological	Procedures are described clearly and concisely so that others can replicate the procedure.
Applied	Investigates socially significant behaviours that are important to the participants.
Conceptually Systematic	Interventions are based upon the existing literature.
Analytic	Established a functional relationship and experimental control.
Behavioural	Includes a precise measurement of behaviours that are observable as the focus of the study.

A comprehensive ABA program was first formally developed by behaviour analysts at the Princeton Child Development Institute (Ferster & DeMyer, 1961). However, ABA did not gain widespread notoriety until two decades later when Dr. O. Ivar Lovaas published his research at UCLA (Lovaas, 1987). These studies were among the first to demonstrate that children with autism and intellectual disability can learn and make improvements to their language and behaviour. It is important to note that during this era, most children diagnosed with autism were at the very severe end of the spectrum. As such, most of the children in Lovaas' 1987 study had severe intellectual disability in addition to autism.

While Lovaas'1987 study garnered much attention, the study was somewhat controversial. Lovaas used electrical shocks as punishment for severe self-injurious behaviour and slaps to the thighs for less dangerous behaviour. Many questioned whether these practices were ethical. Lovaas himself stopped using aversives (slaps, shocks, and other unpleasant stimuli) by the late 1980s because he found that non-aversive methods (positive reinforcement) had become so sophisticated and effective that he felt that aversives were no longer necessary. B. F. Skinner, one of the early pioneers of ABA and behaviourism, echoed these sentiments, stating that punishment and aversives to treat autism symptoms are not only unethical, but less effective than the use of positive reinforcement or reward-based strategies (Skinner, 1968).

2.2.2 Continued controversy regarding applied behaviour analysis.

Even with these declarations, many still believe that ABA is reliant on aversives and punishment. It is worth noting that in the 1960s and 1970s aversives and physical punishment were widely used by other autism therapies, including Treatment and Education of Autistic and Communication Handicapped Children (TEACCH; Sallows, 2000; Schopler, Reichler, & Lansing, 1980). However, it seems that the association of physical punishment and autism has remained more closely linked to behaviour analysis than other approaches. Controversy

around ABA persists and is evidenced by the number of blogs and documentaries both for and against its use (Socially Anxious Advocate, 2015; ABA4All, 2018; The Wall, 2011; Autism: Challenging Behaviour, 2013). Those against ABA state that the therapy is focused on making the child appear 'normal' or become completely compliant to adult demands. While those in favour of ABA state that the goal is not to 'hide' or 'mask' a child's autism, rather it is focused on supporting individuals with autism to build skills, reduce distress and impairment, and improve their quality of life.

The emergence of the neurodiversity movement in the 1990s further propelled the debate. The movement is led by 'high functioning' autistic individuals who believe autism is a condition, not a disorder (Ortega, 2009). Neurodiversity includes all individuals whose brains are 'wired differently', including attention deficit hyperactivity disorder (ADHD), bipolar disorder, dyslexia, and Alzheimer's Disease (Orsini & Smith, 2010). With such a wide range of individuals represented in this one group, there is no one singular agenda of the neurodiversity movement. However, one common stance is people with autism are different, but not less. They should not be forced to 'mask' or hide their autistic traits. Many in this group feel that behavioural interventions are unethical because they try to change the core characteristics of the child.

This view should be considered in light of the requirements set forth by US healthcare insurance companies. Though ABA is used worldwide, most ABA practitioners and training programs are based in the United States (see Section 2.4 for a more detailed description). Additionally, a review of publication trends from 1992-2001 found that 94% of the publications in the field's flagship journal, Journal of Applied Behavior Analysis, were published from authors residing in North America (Dymond, Clarke, Dunlap, & Steiner, 2000). Due to these factors, much of ABA practice and research is a direct result of the healthcare context in the United States, where ABA services are primarily paid for by

healthcare insurance companies. Healthcare insurance companies will only provide coverage for ABA services if an individual has a diagnosis of autism. Coverage also typically has an age cap for services, meaning that when an individual reaches a certain age (typically 18-22 years old) they no longer qualify for services. Furthermore, US healthcare companies will only pay for ABA services if the services can demonstrate *medical necessity*. Medical necessity has been defined by one insurance company, Blue Cross Blue Shield, as:

> "Services or supplies which are required for treatment of illness, injury, diseased condition, or impairment and are consistent with the patient's diagnosis or symptoms; appropriate treatment according to generally accepted standards of medical practice; not provided only as a convenience to the patient or provider; not investigational or unproven; not excessive in scope, duration or intensity; provided at the most appropriate level of service that is safe" (Bergthold, 1995, p. 183).

In order for insurance companies to reimburse practitioners for ABA services, ABA providers must demonstrate that every target in the individual's treatment plan directly links to one of the deficits or symptoms related to the autism diagnosis. Therefore, ABA providers in the US must necessarily target deficits related to core autism symptoms for treatment to be funded. As a result, ABA programmes and plans must explicitly address deficits, which may be off-putting to some individuals in the neurodiversity movement. An additional problem is that changing autism to a difference, rather than a disability, may result in the loss of services to individuals with autism in the US; Insurance companies will not pay for treatment if there is no stated medical diagnosis. Therefore, many ABA practitioners are at-odds with the neurodivergent community on this topic. While the debate remains unresolved, it highlights the importance of the ethical treatment for individuals with disabilities. In order to provide the treatment that is ethical and effective, the field of ABA needs to be regulated,

professionals need to be highly trained with ongoing supervision, and consumers need to be protected from unethical service providers.

2.2.3 Common misconceptions regarding applied behaviour analysis.

Adding to the controversy is an overall lack of clarity surrounding three common misconceptions. These are discussed in detail below:

1. Miscategorising ABA as a treatment for autism instead of a scientific field.

In their widely used ABA textbook, Cooper, Heron and Heward (2007) defined ABA as: "The science in which tactics derived from the principles of behaviour are applied to improve socially significant behaviour and experimentation is used to identify the variables responsible for the improvement of behaviour" (p. 690). Based on this definition, ABA is a scientific approach, not an intervention for autism. It is the techniques, strategies and procedures based on the principles of ABA that serve as the intervention. For example, the Picture Exchange Communication Systems (PECS), discrete trial training (DTT), reinforcement, and prompting are all procedures or strategies based on the principles of ABA, as displayed in Figure 2.1. When ABA is described as a 'treatment for autism', it fails to recognize the basic research that informs treatment strategies based on ABA principles and the applications of the science to other fields (Dillenburger & Keenan, 2009). ABA is not simply something that is 'done' to young children with autism; it is a scientific approach to understanding all behaviour.

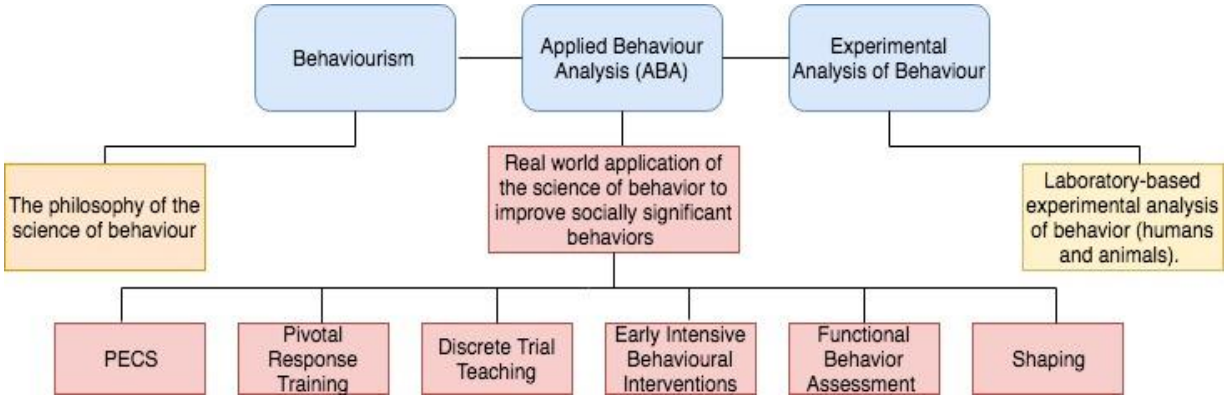

Figure 2.1. Flowchart of the field of behaviour analysis.

2. Conflating ABA with Early Intensive Behavioural Interventions (EIBI)

Another common misconception is that "ABA therapy" consists of 40 hours a week of intensive in-home treatment for young children with autism, stemming from the implementation of Early Intensive Behavioural Interventions (EIBI). EIBI typically consists of 20-40 hours of individualized instruction for young children (Green et al., 2006). EIBI can be delivered in the child's home or at their school. While research suggests that EIBI is a useful intervention for young children with autism, limiting the application of ABA to this one treatment model can be problematic. ABA can be used in a much lower dosage with individuals of all ages who have autism. It can also be useful for individuals without autism (e.g. improving weight loss programs, increasing health and safety, etc.) as identified in Section 2.2.

3. Believing that ABA is synonymous with Discrete Trial Training (DTT)

When many people think of 'ABA therapy', they make the false assumption that ABA consists of one teaching strategy, namely DTT (Stahmer, 2014). DTT is a structured and systematic approach to teaching new skills. DTT was first used in the 1960s and was one of the first interventions to demonstrate an ability to teach children with autism (Schreibman, 1988). DTT involves the presentation of a stimulus (oftentimes an instruction) such as "clap your hands". The child is then expected to clap their hands. If unable to do so, the instructor would provide a prompt (gestural, physical verbal, etc.). If a mistake occurs, an error correction procedure would be implemented. Following a correct response, the instructor would deliver a social or tangible reinforcer to the child. There would then be a brief pause before the next trial would begin. DTT is fast-paced and allows for rapid responding where the student is given a large number of opportunities to respond or practice a response in a short period of time. The skills that can be taught using DTT are varied; some common skills targeted during early intervention programs are vocal imitation ("say 'ball'"), simple

instructions (“give me the ball”), and identification of objects, items or people (“point to your nose”). Early applications of ABA relied heavily on DTT and the therapy sessions appeared to be highly rigid. However, since then additional procedures, such as naturalistic teaching where the instructor follows the child’s lead and uses naturally occurring opportunities to address target behaviours, have been researched and added into ABA programmes to make therapy sessions interactive and child-led. Despite the fact that the field has expanded to include supplementary practices to address the limitations of DTT many fail to recognise this and believe that all ABA lessons consist of is drills (Chiesa, 2005).

2.2.4 Contemporary applied behaviour analysis practice and guidelines.

The Behaviour Analysis Certification Board® (BACB) is the international accreditation body for behaviour analysts. The BACB certifies practitioners at paraprofessional, undergraduate and graduate levels, as shown in Table 2.2. To be fully certified to independently practice ABA, one must obtain status as a Board Certified Behaviour Analyst® (BCBA). This requires a Master’s degree in ABA or a related field, completion of a verified course sequence in ABA, 1500 fieldwork hours supervised by a BCBA and passing an exam to assess knowledge in behaviour analytic skills and client-centred responsibilities. If an individual has met these requirements, in additional to the completion of a PhD in a behaviour analytic topic, they earn the title of BCBA-D (BACB, 2019). The BCBA or BCBA-D carry out the assessment and create the intervention programme for the individual. They may be assisted by a Board Certified Assistant Behaviour Analyst (BCaBA) in these tasks. By assisting with training, supervision, and reports, BCaBA’s allow BCBA’s to oversee more cases and focus their efforts on the most pressing issues. After the programme is created, a Registered Behaviour Technician (RBT®) implements the programme in a 1:1 or group setting under the continued supervision of the BCBA or BCBA-D.

Table 2.2

Certification Requirements for the Behavior Analyst Certification Board

Registered Behaviour Technician (RBT)	**Board Certified Assistant Behaviour Analyst** (BCaBA)	**Board Certified Behaviour Analyst** (BCBA)	**Board Certified Behaviour Analyst Doctoral Level** (BCBA-D)
40 hour course	Verified Course Sequence	Verified Course Sequence	Verified Course Sequence
High School Diploma	Undergraduate degree	Master degree	Doctoral degree
	1000 supervised fieldwork hours	1500 supervised fieldwork hours	No additional fieldwork to the BCBA

Practice guidelines for contemporary treatments based on the principles of ABA have been published by the BACB and have been designed to promote ethical treatment delivery (BACB, 2014). Contemporary treatments are defined and delivered in two ways: focused or comprehensive treatment plans. Focused plans are treatments that are designed to target a limited number of behavioural outcomes. This can be useful for individuals who are missing a few key skills (self-care, safety skills, etc.) or those who need assistance with severe problem behaviours (self-injury, property destruction, etc). Comprehensive programmes, including EIBI, target a wide range of behaviours and developmental domains, such as communication, cognition, social skills, emotional regulation, adaptive functioning and maladaptive behaviours (e.g., tantrum, aggression, non-compliance). These programmes are often delivered at a high intensity (up to 40 hours a week). Both focused and comprehensive treatment programmes can be implemented in a variety of settings, including homes, schools, clinics/outpatient setting, residential facilities, or hospitals.

2.2.5 Evaluation of Applied Behaviour Analysis Research

Over the last 40 years, a significant number of peer-reviewed research studies have been published describing the evaluation of the use of ABA strategies to teach children and adults with autism social, communication, and daily living skills along with decreasing maladaptive behaviours. Difficulties arise when evaluating the research as there is no single, clear definition of "ABA" (Broadstock, 2009). The continued use of phrasing such as "ABA therapy" by researchers, parents, and even many behaviour analysts perpetuates this confusion (Prizant, 2009). The use of more precise language would improve the process of evaluating the research on this treatment. Some studies use the term ABA as synonymous with Early Intensive Behavioural Interventions (EIBI). Other ABA studies focus on a specific teaching strategy that is based on the principles of ABA. Studies that used the term ABA to refer to EIBI comprise a small number of randomized control trials (RCTs). While the latter

group of studies represent the majority of research (over 2,000 publications) analysing the effectiveness of a single or a few techniques. Most of these studies employ single case designs, using reversal or multiple base-line designs or variations of either.

Reversal designs are experiments where the researcher attempts to "reverse" responding to initial baselines levels after successfully implementing the independent variable, then reintroducing the independent variable to demonstrate the experimental control the independent variable has over the dependent variable. A commonly used version of this is A-B-A-B design. The initial baseline phase (A) is assessed until there is a steady rate of responding. Then, the independent variable (B) is introduced and implemented until a steady state of responding is established. Following this, the independent variable is removed, and the dependent variable is expected to return to baseline levels (A). Once a steady state of responding at the baseline level is once again established, the independent variable is reintroduced (B). For example, one study assessed the effects of a classroom behaviour management intervention on problem behaviours for a sixth-grade class (De Prey & Sungai, 2002). Baseline data was collected and demonstrated high rates of problem behaviour. The intervention was introduced, and the level of problem behaviour decreased. The intervention was withdrawn and the level of problem behaviour increased. When the intervention was reintroduced, problem behaviour once again decreased (see Figure 2.2).

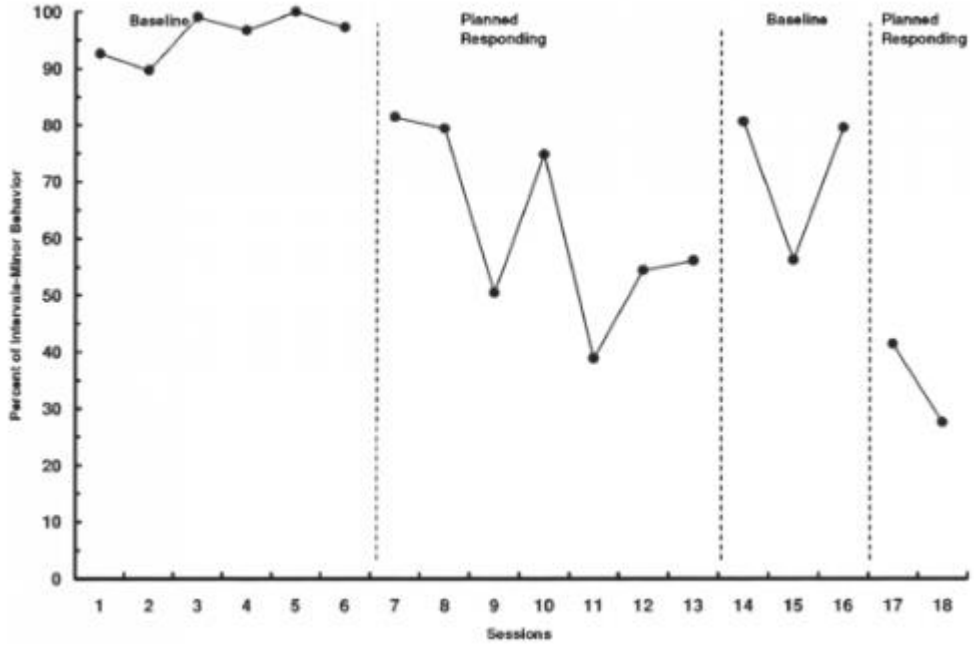

Figure 2.2. Example of an A-B-A-B design. This study examined the effects of a behaviour management intervention to reduce problem behaviour in a sixth-grade classroom. The 'planned response' phase represents the intervention to reduce problem behaviour in a sixth-grade classroom. The ‘planned response’ phase represents the intervention.

Source: From De Prey, R. L. & Sugai, G (2002). The effect of active supervision and precorrection on minor behavioural incidents in a sixth-grade general education classroom. Journal of Behavioral Education, 11, fig.1, p. 261. Copyright 2002 by Human Sciences Press.

Multiple baseline design studies utilize a concurrent measurement of two or more behaviours in a baseline condition. The independent variable is sequentially introduced to one of the behaviours while the baseline conditions are maintained with the other behaviour(s) (Baer, Wolf, & Risley, 1968). After behaviour change occurs in the first behaviour, the independent variable is introduced to the second behaviour, while any remaining behaviours are kept at baseline conditions. Experimental control is demonstrated when the behaviour change occurs in for each behaviour only when the independent variable has been introduced. Multiple baseline studies can be implemented across different behaviours of a single participant, the same behaviour across two or more participants, or the same participant in two or more settings. For example, a multiple baseline across participants design could be used to examined new requests for items by children with autism (saying "I want ball."). A baseline of three child participations would initially be collected. The intervention would then be introduced for only one participant, while the other two participants would remain in baselines conditions. If behaviour change occurred (participant one demonstrated an increase in requesting), the intervention would be administered to participant two, while keeping participant three in baseline conditions. Once behaviour change occurred in participant two, the intervention would be introduced to participant three. If the introduction of the intervention corresponded with increases in requesting for all three participants only after the intervention was introduced, the results would suggest that the intervention was successful in increasing requesting in these participants.

A multiple probe design is a variation of a multiple baseline design that uses intermittent instead of continuous measurement during baseline (Horner & Baer, 1978). By strategically collecting intermittent data points instead of collecting data on all sessions, researchers save time and resources. An example of a multiple probe design is depicted in Figure 2.3.

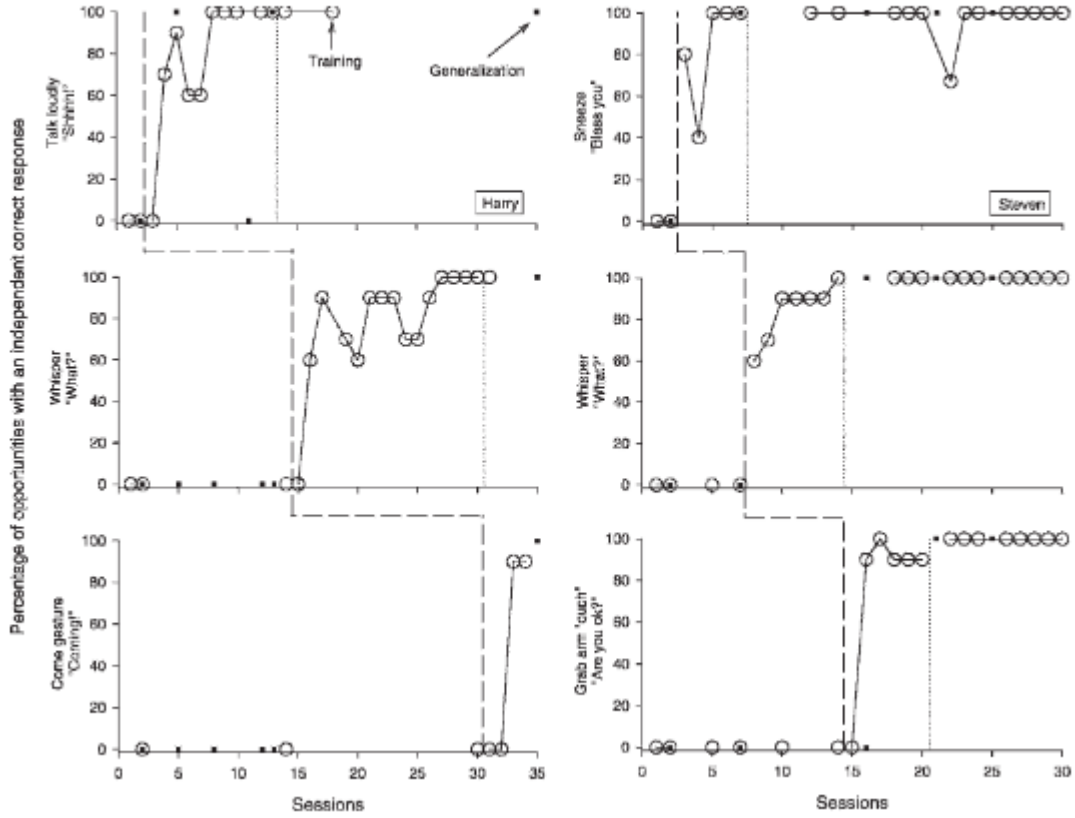

Figure 2.3. Example of a multiprobe multiple baseline design. Percentage of opportunities with an independent correct response for Harry and Steven across three communicative responses during baseline and intervention as well as performance during generalization probes. The dashed line indicates when intervention began; the dotted line indicates when mastery (i.e., performing at or above 80%across two consecutive sessions in which teaching opportunities were interspersed with previously mastered responses, across 2 days and two teachers) occurred.

Source: From Jones, E. A. & Feeley, K. M. (2007). Teaching spontaneous responses to young children with autism. Journal of Applied Behavior Analysis, 40, p. 569. Copyright 2007 by the Journal of Applied Behavior Analysis.

Additional components of single-case design research are social validity and procedural integrity. Social validity is "estimation of the importance, effectiveness, appropriateness, and/or satisfaction various people experience in relation to a particular intervention" (Kennedy, 2005, p. 219). While this concept had been present in other fields, such as medicine, psychology, and medicine, it was first brought to the field of ABA by Kazdin and Wolf in the late 1970s (Kennedy, 2005). Wolf (1978) identified three main foci of social validity: social importance of treatment goals, acceptability of treatment designs and procedures within the community setting, and the significance of treatment outcomes. These concepts have helped shape modern social validity measures. Social validity measure may be collected by the consumer of treatment themselves or relevant stakeholders (parents, teachers, staff, etc). Measure may include Likert scale ratings or opened-ended questions that are typically subjective in nature (Carr, Autsin, Britton, Kellum, & Bailey, 1999). It has been suggested that information obtained through social validity questionnaires be used when creating intervention programs to ensure they are relevant to and supported by the community (Schwartz & Baer, 1991).

Procedural integrity (also known as procedural fidelity, treatment fidelity, and treatment integrity) is the extent to which treatment implementation is carried out as planned (Cooper, Heron, & Heward, 2006). Low treatment integrity in a confounding variable in research that makes it difficult to reliably analyse results. If the desired outcomes are not achieved, it is unclear if that would be due to an ineffective treatment or just poor implementation. At the same time, if desired outcomes are achieved it would be difficult to show experimental control was obtained by the intervention described in the research protocol or if it was due to an extraneous variable. Poor treatment integrity can be caused by experiment bias can occur when the experimenter implements the intervention with unfair advantages over baseline conditions. Treatment drift, where those implementing the invention

alter the way the intervention is delivered, may also occur. This be done knowingly or unknowingly. For example, complex interventions may not be delivered accurately due to the multifaceted nature of the intervention. Treatment drift may also occur when those responsible for implementing the intervention only implements components of the intervention that they favor. For example, a therapist may only implement the aspects they believe are effective and only utilize the additional components when the researcher is present for observation. In order to prevent treatment drift and promote procedural integrity, three key steps should be take: researchers should include precise definitions of treatment procedures, the procedures should be simplified and standardized as much as possible, and treatment integrity should be regularly monitored and assessed (Cooper, Heron, & Heward, 2006).

The dominance of single-case design research in the field of ABA, as opposed to the RCTs in other fields of psychology, reflects the focus of the field. This type of design allows for the examination of individual behaviour change as a function of changes in the environment (Kazdin, 2010). Single-subject designs that employ rigorous methodology contribute valuable information to the evidence for different interventions, particularly when evaluating interventions where large-scale studies are not feasible (Kazdin, 2010). However, difficulties arise in the evaluation of these studies, as there is no agreed upon method for synthesizing these experiments and analysing them in a meta-analysis (Kratchowill et al., 2013).

Few RCTs have been conducted to assess the effectiveness of ABA. Typically, these RCTs are evaluating EIBI, not individual techniques (New Zealand Guidelines Group, 2009). The lack of RCTs evaluating ABA is commonly pointed out (Morris, 2009). However, others have argued that while RCTs are well equipped to study pharmaceutical interventions, they are not designed for the field of ABA (Keenan & Dillenburger, 2011). Since ABA is a

science, not an intervention as previously discussed, conducting an RCT for ABA would be akin to performing an RCT of nursing. Simonoff (2018) further identified two challenges to the use of RCTs to assess autism interventions. First, concealment of allocation to a treatment group may not be possible. Secondly, there are issues with outcome measures used in RCTs. Many of the outcome measures used rely on human observation of participation behaviours, which can be time consuming and is vulnerable to human errors.

Despite the challenges of performing RCTs for autism or 'ABA therapy', researchers from within the field of behaviour analysis have called into question the reliance on single subject design research and lack of RCTs. Critchfield and Reed (2017) identified the seven dimensions of behaviour analysis as described by Baer, Wolf, and Risley (see Section 2.2.1) as a bottleneck to the expansion of ABA research. In their article, they argue that these seven dimensions have become the requirement for ABA research and failure to satisfy every requirement leads to the rejection from the field's flagship journal, JABA. As described in Table 2.1, in order for a study to meet the requirement for *behavioural*, the study must observe participant's behaviors. Questionnaires and data analysis based upon group means does not allow for the examination of individual behavior change. Therefore, group designs would fail to meet the requirements for ABA research. Critchfield and Reed claim that JABA's strict adherence to these requirements prevents socially-significant research from being published and disseminated within ABA research. Further, group-designs would not meet the seven dimensions because it would not be sufficiently *Analytic*, as the results are not captured and analysed with-in subject. Friman (2017) echoed their sentiments and pushed for the field to adopt a wider approach to research design. Future research needs to address these factors, given the reliance on RCTs by large organization for the basis of medical and educational recommendations (i.e., NICE guidelines).

Currently, four meta-analyses (Eldevik et al., 2009; Ospina et al., 2008; Reichow & Wolery, 2009; Spreckley & Boyd, 2009) and six systematic reviews (Blue Cross and Blue Shield Association, 2009; Case-Smith & Arbesman, 2008; Howlin, Msagiati, & Charman, 2009; Rogers & Vismara, 2008; Seida et al., 2009; Eikeseth, 2009) have been performed to assess the effectiveness of interventions based on ABA. Of the 10 reviews, only four included single-subject design studies (Ospina et al., 2008; Rogers & Vismara, 2008; Seida et al., 2009; Eikeseth, 2009) indicating that many reviews are missing a large amount of evidence. Most of the reviews provide broad support for the use of ABA with children and adults with autism. Eikeseth (2009) found that ABA treatment is effective for improving global functioning in young children. Several reviews found that early intensive behavioural interventions improve IQ in young children with autism (Howlin, Magiati, & Charman, 2009; Reichow & Wolery, 2009; Rogers & Vismara, 2008). Though Rogers and Vjsmara (2008) found improvements in IQ, language, communication, and severity of autism symptoms, they noted that research still needs to be completed to determine what interventions produce the best outcomes. Limitations were noted in most reviews, often with re-occurring themes. Methodological issues were present in many studies where intervention intensity was not properly controlled for. Howlin et al. (2009) stated that research needs to be conducted to assess the optimal dosage of treatment, age at the onset of treatment, and other child characteristics that predict positive outcomes to ABA treatment. All four meta-analyses call for additional research with larger effect sizes to determine what treatment characteristics lead to the best outcomes (Eldevik et al., 2009; Ospina et al., 2008; Reichow & Wolery, 2009; Spreckley & Boyd, 2009).

Though limitations in the research exist, several governmental agencies and nationally recognized federal research institutes have issued statements and policies supporting the use of ABA for children and adults with autism (Agency for Healthcare Research and Quality,

2014; National Institute of Mental Health, 2008; Center for Medicare & Medicaid Services, 2011, 2010). Several medical institutes, including the American Academy of Paediatrics, have also published clinical practice guidelines that support the use of interventions based on the principles of ABA (Myers & Johnson, 2007). In 2001 Indiana became the first state to pass legislation requiring insuring companies to provides services based on the principles of ABA as a treatment for autism. Since then, all 50 states have passed law mandating ABA coverage by insurance companies. In response to the growing demand for services based on the principles of ABA, 31 states have created licensure laws to regulate the practice of ABA within since 2009 (Association of Professional Behavior Analysts, 2019). As the field continues to grow, it is imperative that rigorous research is conducted to identify the key components of effective treatments.

2.2.6 Issues with the international development of services.

Outside of the USA, services remain out of reach for many individuals with autism and their families. This is largely due to a lack of highly qualified professionals, availability of training and cost of therapy. While it is an international certification, most Board Certified Behaviour Analysts reside in the USA. There are currently 37,859 BCBAs, of which only 3,184 reside outside of the USA (BACB, 2020). There are currently 399 Verified Course Sequences (VCS) in the United States, while there are only 110 outside of the United States, located in 44 countries (ABAI, 2020). For those not residing in the United States or one of the 44 countries with a VCS, the distance programs in the USA are often too expensive, leaving training inaccessible. For families living in countries without BCBAs, it is often too costly to bring them in for treatment.

In addition, it is problematic that ABA, in most cases, is unregulated. Apart from the USA where 30 states have laws to license or regulate the field of ABA, there is no legal oversight for the field (APBA, 2018). Anyone can claim to be an 'ABA expert' and provide

'ABA therapy'. Often, these individuals lack extensive training and supervision. This commonly leads to poor practice, ineffective and even unethical treatment methods, further perpetuating negative opinions of ABA (Dorsey, Weinberg, Zane, & Guidi, 2009). Families and other consumers of ABA are often are unaware of the professional credentials and do not know how to assess the competency of an ABA provider. Families are charged high fees for programmes that inevitably fail due to the lack of knowledge and training of the practitioner or service provider. Failure of governmental bodies to recognize and regulate the field prolong this issue.

2.2.7 Evidence-based practices for children and adolescence with autism.

Evidence-based practice (EBP) is "an approach toward treatment delivery that is grounded in the fundamental principle that decisions on treatment selection should be made on the strength of scientific evidence that demonstrates that the treatment does what it is intended to do" (Zane, Weiss, Davis, & Melton, 2016, p.487). This approach has been adopted by a range of fields, such as audiology, speech-language pathology, dentistry, nursing, psychology, social work, and education. With this approach, practitioners make decisions based on (1) the scientific evidence, (2) their clinical experiences, and (3) their client's values. This requires service providers to critically evaluate conventional practices and update their services to be in line with the most up-to-date scientific research in their respective field.

This approach has been adopted by a number of large organizations and governing bodies in the field of special education. Organizations, such as the American Psychological Association (APA), BACB, American Speech-Language-Hearing Association (ASHA), Council for Exceptional Children (CEC), Main Department of Health and Human Services (MAINE), National Autism Center (NAC), National Council on Disabilities (NCD), National Professional Development Center (NPDC), New York State (NYS), What Works

Clearinghouse (WWC), and Wing Institute (Wing; Zane, Weiss, Davis, & Metlon, 2016). These institutions have all published standards for what constitutes an EBP and while there are differences between the various standards, this highlights that there is support for the use of EBPs across a range of fields that serve individuals with autism.

Historically, EBPs for children with autism were identified by narrative reviews (e. g. Simpson, 2005). Though these studies were systematic in nature, there were several shortcomings; they did not include clear inclusion and exclusion criteria and many did not include single subject design studies and, therefore, omitted a large portion of autism intervention literature. The first review to address these limitations was published in 2009 by the National Standards Project (NSP) at the National Autism Center. This review evaluated studies performed up to 2007 and identified 11 established treatments, 22 emerging treatments (demonstrating some effectiveness but needing further research), and five interventions that had no effect. The NPDC conducted a separate review analysing articles from 1997-2007. This review found 24 treatments that met the criteria for evidence-based. The two reviewed yielded similar results; Nine of the 11 treatments identified by the NSP review as evidence-based treatments were also identified by the NPDC. Five of the six interventions identified by the NPDC as evidence-based were identified as emerging treatments by the NSP. The differences between the two reviews in the number of treatments identified are due to classification differences. For example, the NSP identified behavioural package as one established treatment, whereas the NPDC identified seven separate components of the behavioural package (task analysis, discrete trial training, functional behaviour analysis, functional communication training, response interruption/redirection, and differential reinforcement) as stand-alone practices.

Wong et al. (2013) followed the protocol used the NPDC standards to conduct an updated review of research conducted from 1990-2011. The review assessed behavioural,

developmental and/or educational interventions for participants between birth and 22 years old with a diagnosis of autism, pervasive developmental disorder (PDD), or high-functioning autism. Participants with co-occurring conditions, including intellectual disability, genetic syndrome (e.g., Fragile X, Down syndrome), seizure disorder, mental illness (e.g., anxiety, depression, obsessive compulsive disorder), attention deficit/hyperactivity disorder x(ADHD), physical disability (e.g., cerebral palsy, orthopedic impairment), sensory impairment (e.g., hearing or visual impairment), or learning disability were included in the review. The criteria for qualification as an EBP was:

1. At least two high quality experimental or quasi-experimental group designs conducted by at least two different researchers or research groups.

OR

2. At least five high quality single case design articles conducted by at least three different researchers or research groups, with at least 20 participants across studies.

OR

3. A combination of at least one high quality experimental or quasi-experimental group design article and at least three high quality single case design articles conducted by at least two different research groups.

The review analysed 456 articles and found 27 interventions that met the standards for EBPs. Of the 27 interventions, 17 interventions are based on the principles of ABA. An additional six interventions have elements of ABA and are commonly used by BCBAs. However, the inclusion of group and single-subject designs meant that this review was unable to calculate an effect size for ABA treatment, as there is no agreement on the best practice for this process (Kratchowill et al., 2013). The review also failed to include participant

demographic information, which may have led to important findings. Additionally, the study did not identified practices with limited or no support. Despite these limitation, this review suggests that ABA strategies represent a large portion of EBPs for use with children and adults with autism.

NICE guidelines (2013) state that autism interventions should be based on scientific evidence. In the USA, the Individuals with Disabilities Education Act (IDEA; 1997) and No Child Left Behind (NCLB; 2002) both require that EBPs be used when educating individuals with disabilities. Despite the requirements to use EBPs, the majority of special education teachers have not been formally trained to implement EBPs. Instead, they use teaching strategies based on personal preference, past experiences and recommendations from colleagues (Cook, Tankersley, & Landrum, 2013) and do not consistently implement EBPs (Hess, Morrier, Heflin, & Ivery, 2008; Schreck & Mazur, 2008). There is a major gap between the requirements of health and education policy guidance to use EBPs, and their use by educators (Fixen & Blasé, 1993; Neef, 1995; Odom, et al., 2005; Page, Iwata, & Reid, 1982; Shreck & Mazur, 2008).

The lack of training in EBPs for teachers and professionals needs to be addressed to improve the health and educational outcomes for children with autism. Research is needed to determine the most effective ways to teach educators to use EBPs and how to promote and maintain fidelity to their use in the classroom. Effective training will help close the gap between the requirements for the use of EBPs and the effective implementation of these strategies by educators.

2.3 PART 3: Behavioural Skills Training

Traditional staff training is delivered in didactic form, with the instructor providing information to the student. This can be effective for teaching knowledge but is considered largely ineffective for teaching competency and skills (Alavosius & Sulzer-Azaroff, 1990;

Petscher & Bailey, 2006). Behavioural Skills Training (BST) is a well-established training package based on the principles of ABA that is designed to teach professionals to implement ABA procedures (Parsons, Rollyson, & Reid, 2012). BST has been shown to be an effective method of teaching a variety of skills, including the Picture Exchange Communication System (Homlitas, Rosales, & Candel, 2014), behaviour management techniques (Miles & Wilder, 2009; Sawyer, Crosland, Miltenberger, & Rone, 2015) and functional analysis (Ward-Horner & Sturmey, 2012). The most recent RBT training guidelines published by the BACB state that RBT training should be "designed using behavioural-analytic instructional procedures (e. g. programmed instruction, behavioural skills training)", highlighting its acceptance and importance in the training of ABA practitioners (BACB, 2019).

2.3.1 Components of behavioural skills training packages.

BST involves four basic components:

1) Instruction. The first component is a verbal and/or written instruction. The purpose of the instruction is to provide a rationale for the target skills and how to complete the skills successfully. This is the approach typically employed in traditional training courses.

2) Model. This component involves either the demonstration of the skill by the instructor, or a video model. The objective of the model is to show the target skill or behaviour to the trainee.

3) Rehearsal. This component requires the trainee to practice the skill in a role-play or real-life setting.

4) Feedback. After the rehearsal the instructor gives feedback to the individual trainee or group. If the skills were demonstrated correctly, positive feedback is given. If the skill is not performed correctly, corrective feedback is given. The trainee then rehearses or practices the skill and receives feedback until the skill is mastered.

Most BST research has focused on teaching one EBP (e.g. discrete trial teaching) to a small group of participants, using a multiple baseline across participants deign. One study at a large American university used BST to teach seven undergraduate pre-service special education teachers to implement seven EPBs in role play scenarios (Sawyer et al., 2017). In this study, Sawyer et al. selected seven EBPs from the National Professional Development Centre on Autism Spectrum Disorder's list of EBPs (NPDC). The researchers used a pre- and post- test design to compare participant performance of EBPs based on traditional teaching and BST. The researchers first provided a traditional, PowerPoint lecture on the EBP. Then they tested the participants' ability to perform that EBPs in a role play scenario. The researches then completed the full BST protocol (model, rehearsal, and feedback). After the BST, the researchers assessed the participants' performance of EBPs in a role play scenario. They found that the student participants performed better on all EBPs when they have received BST in addition to the lecture. Students also found BST to be an acceptable form of training. This suggests that university courses can be enhanced from the incorporation of BST, and that this approach can successfully engage students. However, the study failed to assess the long-term maintenance of the skills taught and students went on to apply these skills in their work with children.

2.3.2 Systematic review of behavioural skills training literature.

Given the recent rise in BST publications and its inclusion in the new RBT training requirements (BACB, 2019), a review of the literature is important to identify the breadth,

findings, and limitations of this approach. This section will provide an overview of the current state of evidence for BST and identify strengths as well as gaps in the literature.

i. Method

Inclusion/Exclusion Criteria

Peer-reviewed articles were included in the review if they met the following criteria: the term 'behavioural skills training' was specifically used and the study used all four components of BST to train an individual to implement a performance skill. The performance skills must be an ABA procedure, evidence-based practice, or additional skills necessary for implementing an ABA program (e.g., data collection). The main dependent variable must be participant demonstration of the performance skill and include data on that performance. Studies were excluded if the main dependent variable was not an ABA procedure (e. g. safety skills, swimming, etc). Studies were also excluded if BST was used in conjunction with another form of training (e.g. social skills training) as this would make it unclear which component of the training the participant was responding to. Additionally, case studies and dissertations were excluded. There were no parameters on the date of publication in order to evaluate the body of literature on BST in its entirety.

Search Strategy

The literature review was conducted on January 1st, 2018 and is shown in Figure 2.4. Using the key terms "behavio* skill* train*" and "BST", a search conducted in Web Of Science, PsycInfo, and ERIC, identified 64 articles. The articles were reviewed by two researchers and 34 met the inclusion criteria. The Journal of Applied Behavior Analysis (JABA), Journal of Organizational Behavior Management (JOMB), and Behavior Analysis in Practice (BAP) were hand searched as they yielded the most results from the initial search. Hand searching the journals did not produce any additional articles.

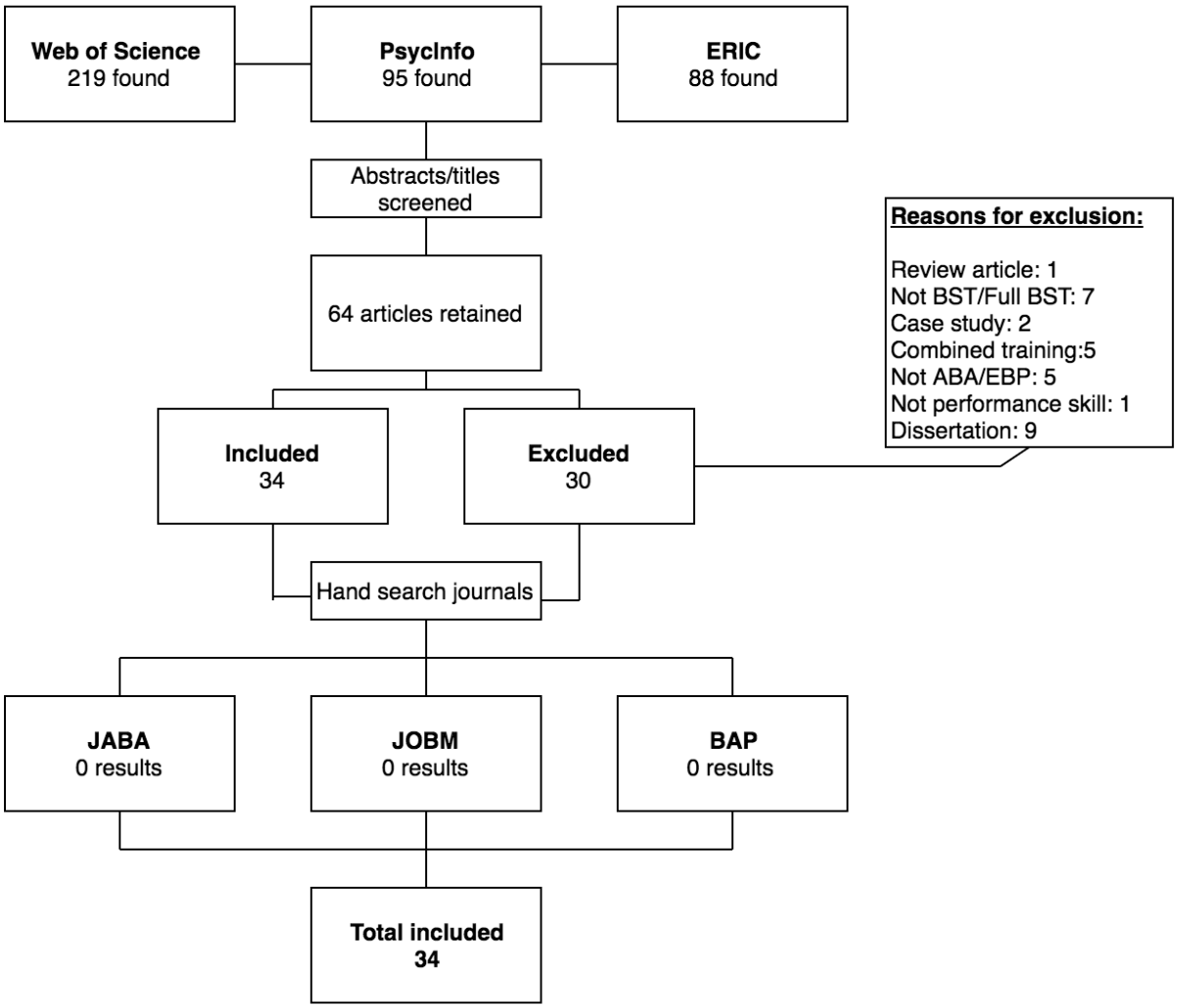

Figure 2.4. Search strategy for behavioural skills training systematic review. ABA, Journal of Applied Behavior Analysis; JOMB, Journal of Organizational Behavior Management; BAP, Behavior Analysis in Practice.

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Methodological Quality Evaluation

A systematic approach was taken to evaluate the methodological quality of the articles identified in this study. Wendt and Miller (2012) compared seven different quality appraisal tools to determine which tools most effectively assessed the methodological quality of sing-subjects experimental research. Of the tools analyzed, the Evaluative Method (Reichow, Volkmar, & Cicchetti, 2008;) was found to have the highest validity and reliability. The Evaluative Method consist of three components:

1. A rubric for determining the research at two levels, the primary and secondary indicators. The primary indicators are ranked as either high, acceptable or unacceptable. These indicators represent the critical design elements for high quality research and include participant characteristics, independent variable, dependent variable, baseline condition, visual analysis, and experimental control. Secondary indicators include elements that are valuable, but not required. These include interobserver agreement, Kappa, fidelity, generalization and/or maintenance, and social validity. Secondary indicators are rated as either evidence or not evidenced. A detailed description of primary and secondary indicators can be found in the appendix.
2. A method for synthesizing results from the rubric to assign a strength score (strong, adequate, or weak) to the research study. These scores take into consideration the number of primary and secondary indicators present, as well as the number of 'unacceptable' elements (see Table 2.3).
3. An instrument to determine the level of evidence a particular intervention ("promising" or "established"). Theses scores are determined by the amount of research studies classified as 'strong' or 'adequate', the number of independent research, the number of locations, and total sample size of participants.

The Evaluative Method was initially created to evaluate autism treatment studies, but has been adapted for use in research studies training individuals to use ABA strategies through Telehealth (Tomlinson, Gore, & McGill, 2018). The modifications made by Tomlinson and colleagues were adopted for this review; The ratings of 'Borderline Adequate' and 'Borderline Strong' were included to illustrate the range in the quality of research. The 'participant' criteria were expanded so that studies could receive a 'high' rating if relevant diagnostic information was not included (the primary participant were the trainees who did not necessarily have a diagnose. This requirement was only applied when relevant). Some studies included multiple experiments. In these cases, the tool was applied separately for each experiment in that article. Only one article identified in this review was a group design study and did not meet the requirements of the Evaluative Method (sample size too small) and was therefore not included in the quality evaluation.

Table 2.3

Criteria Used to Assign Final Ratings on the Evaluative Method

Rating	Criteria
Strong[a]	'High" on all primary indicators Evidence of 3 or more secondary indicators
Borderline Strong[b]	'High' on 5 primary indicators, no 'Unacceptable' on any primary indicators Evidence of 3 or more secondary indicators
Adequate[a]	'High' on 4 primary indicators, no 'Unacceptable" on any primary indicators Evidence of 2 or more secondary indicators
Borderline Adequate[b]	'High' on 3 primary indicators, no more than 1 primary indicator rated as 'Unacceptable' Evidence of 2 or more secondary indicators
Weak[a]	'High' on less than 3 primary indicators, or 2 or more primary indicators rates as 'Unacceptable' Evidence of less than 2 secondary indicators

[a]Criteria unchanged from Reichow (2008). [b]Criteria unchanged from Tomlinson (2018).

ii. Results

Research Trends and Context

The earliest study identified that met inclusion criteria was published in 2004. Fourteen percent of studies were conducted between 2004 and 2010 (*n* = 5) and 20% of the studies were performed in 2017 (*n* = 7), demonstrating a steady growth in publications. The studies were published in 13 different journals, with 34% (*n* = 12) of the studies appearing in the *Journal of Applied Behavior Analysis* (JABA), followed by *Behavioural Interventions, Journal of Organizational Behavior Management (JOBM),* and *Research in Autism Spectrum Disorders* with three studies on this topic published in each. Most of the studies took place in the United States of America (*n* = 31), with additional studies taking place in Saudi Arabia, the United Kingdom, and the Netherlands (Eid et al., 2017; Giles et al., 2018; Palmen et al., 2018). There were a total of 111 unique authors (M = 3.7 per paper), with nine researchers appearing twice (Crosland, Hawkings, Lerman, Miltenberger, Rosales, Sarokoff, Sawyer, Sieverling, & Wikler) and one researcher authoring nine separate studies (Sturmey). Most studies were multiple-base line designs (*n* = 29), with two featuring a pre/post-test design (Matthews & Hagopian, 2014; Sawyer et al., 2017), two multiple probe (Belisle et al., 2016, Featherstone et al., 2014) and one group design (Matthews et al., 2014).

Table 2.4

Study Characteristic from Articles Included in Behavioural Skills Training Review

Authors	Journal	Adult participants	Participant age	Learner participants	Learner age	Procedure
Giles, Swain, Quinn, & Weifenbach, (2018)	Behavior Modification	3 female teaching assistants	26, 26, 33	3 males with autism and stereotypy	6, 9, 12	RIRD
Sawyer, et al., (2017)	Behavior Analysis in practice	7 female undergraduate special education majors	19-23	--	--	LTMP, FCT, DRO, CTD, Naturalistic intervention, RIRD MSWO preference assessment
Dogan, et al., (2017)	JABA	4 female parents	37-47	4 males with autism, Asperger's or PDD-NOS	9, 9, 10, 12	Social skills- joining the conversation and asking for help
Subramaniam, et al., (2017)	J. Behavioral Education	4 female parents	29, 43, 30, 37	4 males with autism	2, 7, 8, 11	DTT
Belisle, Rowsey, & Dixon, (2016)	JOBM	1 female and 1 male direct care staff	37, 63, 28	3 males with autism	16, 17, 21	PEAK
Sawyer, Crosland, Miltenberger, & Rone, (2015)	Child & Family Therapy	2 females and 1 male parent	27, 39, 70	3 males typically developing who display problematic behaviour	2, 3, 3	Reinforcement, Pivot and/or redirect-use reinforcement
Homlitas, Rosales, & Candel, (2014)	JABA	3 teachers (gender NR)	NR	9 children with autism (gender NR)	2-7yrs	PECS 1-3A

Featherston & Sturmey, (2014)	Research in Developmental Disabilities	4 female and 2 male instructors	NR	Individuals with a developmental disability (gender NR)	3-12 years	DTT, incidental teaching, activity schedule following
Matthews, & Hagopian, (2014)	JOBM	3 teaching assistants (gender NR)	24-39	--	--	Data analysis
Lerman, Hawkins, Hofman, & Caccavale, (2013)	JABA	3 females and 1 male with autism	21, 25, 29, 30	1 female with autism	4	DTT
Shayne & Miltenberger, (2013)	Behavioral Interventions	6 female and 2 male foster parents	NR	--	--	ABC data, summary statement, treatment selection
Graudins, Rehfeldt, DeMattei, Baker, & Scaglia, (2012)	Research in Autism Spectrum Disorders	3 female dentist/ dental students	NR	3 female and 1 male with autism and low-moderate levels of intellectual disability	3, 3, 4, 4, 4, 5, 5, 7	Differential reinforcement, escape extinction
Seiverling, Williams, Sturmey, & Hart, (2012)	JABA	3 female parents	33, 41, 40	3 males with autism and food selectivity	4, 5, 8	Taste exposure, escape extinction, fading
Hsieh, Wilder, & Abellon, (2011)	JABA	2 female and 1 male parent or respite care worker	24, 32, 41	2 female and 1 male child with autism and marked language deficits	8, 8, 10	Incidental teaching
Nigro-Bruzzi & Sturmey, (2010)	JABA	3 special education teachers and 3 speech therapists (gender NR)	NR	6 children with autism (gender NR)	2, 2, 4, 4, 4, 6	Mand training

Rosales, Stone, & Rehfeldt, (2009)	JABA	2 female undergraduate and 1 female graduate rehabilitation students	NR	--	--	PECS 1-3
Miles & Wilder, (2009)	JABA	3 female caregivers (mother, kindergarten teacher, nanny)	NR	1 female and 2 male children with autism, learning disability or typical development	4, 6, 6	Guided compliance
Sarokoff & Sturmey, (2008)	Research in Autism Spectrum Disorders	3 female teaching instructors	NR	5 male children with autism	M=5	DTT
Lafasakis & Sturmey, (2007)	JABA	3 female parents	35, 48, 50	2 male children with autism, 1 male child with Down syndrome	4, 4, 4	DTT
Sarokoff & Sturmey, (2004)	JABA	3 special education teachers (gender NR)	NR	1 child with autism (gender NR)	3	DTT
Hogan, Knez, & Kahng, (2015)	Journal of Behavioral Education	4 female instruction staff (non-licensed teachers)	25-34	2 children with autism or other developmental disability (gender NR)	NR	BIP- NCR, DRA, EXT, FCT
Lerman, Hawkins, Hillman, Shireman, & Nissen, (2015)	JABA	1 female and 4 male adults with autism	20, 21, 22, 23, 23,	11 children with problem behaviour (gender NR)	3, 4, 4, 5, 5, 6, 7, 7, 7, 7, 7	Incidental teaching; DTT

Eid, et al. (2017)	Journal of Developmental and Physical Disabilities	3 female parents	32, 37, 38	3 children with autism	3, 6, 7	Natural language paradigm
Higgins, Luczynski, Carroll, Fisher, & Mudford, (2017)	JABA	3 female direct-care staff	21, 23, 24	1 female and 2 male children with autism	4, 5, 5	MSWO preference assessment
Drifke,Tiger, & Wierzba, (2017)	Learning and Motivation	2 female and 1 male parent	42, 45, 47	1 male with autism and 1 male with Down syndrome and ADHD	10, 11	3-step prompting: DRA, delivering positive/neg reinforcement
Jenkins & DiGennaro Reed, (2016)	JOBM	17 female and 1 male undergraduate students	17-22	--	--	Functional analysis
Miller, Crosland, & Hewitt, (2014)	Child and Family Behavior Therapy	3 female special education teachers	30-59	--	--	Classroom management: reinforcement, pivot, redirect-use reinforcement, set expectations, stay close.
Gianoumis, Sieverling, & Sturmey, (2012)	Behavioral Interventions	3 female preschool teaching assistants	25, 28, 34	3 female and 3 male children with autism	3-4	Natural language paradigm; MSWO preference assessment
Ward-Horner & Sturmey, (2012)	Behavioral Interventions	3 female teaching assistants	NR	2 male children with autism and aggressive behaviour	9, 10	Functional analysis
Nosik, Williams, Garrido, & Lee, (2013)	Research in Developmental Disorders	3 direct-care staff in BST condition (gender NR)	36, 28, 24	1 adult with autism (gender NR)	39	DTT

Palmen, Didden, & Korzilius, (2010)	Research in Autism Spectrum Disorders	2 female and 2 male staff members at a treatment facility	41-50	Adolescents with autism	NR	Reinforcement, error correction
Maffei-Almodovar, Feliciano, Fineup, & Sturmey, (2017)	Behavior Analysis in Practice	3 special education teachers (gender NR)	NR			Graph analysis
Dart, Radley, Furlow, & Murphy, (2017)	Behavior Analysis: Research and Practice	4 male high school students	NR	4 high school students with autism and intellectual disabilities	NR	DTT
Loughrey, et al. (2014)	Analysis of Verbal Behavior	2 female and 1 male caregivers	2 between 30-40, 1 between 60-65	1 female with fragile X and 1 male with either autism	3, 12	MSWO preference assessment, DR, incidental teaching, errorless learning, vocal shaping, data collection, and error correction

Notes: JABA Journal of Applied Behavior Analysis, *JOMB* Journal of Organizational Behavior Management , *NR* information not reported, *RIRD* response interruption-redirection, *LTMP* least-to-most prompting, *FCT* functional communication training, *DRO* differential reinforcement of other behaviour, *MSWO* multiple stimulus without replacement, *DTT* discrete trial training, *PEAK* Promoting Emergence of Advanced Knowledge, *PECS* Picture Exchange Communication System, *IT* incidental teaching, *ABC* antecedent, behaviour, consequence, *BIP* behaviour intervention plan, *NCR* noncontingent reinforcement, *DRA* differentia reinforcement of alternative behaviour, *EXT* extinction, and *CTD* constant time delay.

Trainee Characteristics

The articles in this review featured 139 participants in total who received BST, including 97 females, 21 males, and 21 participants whose gender was not reported in six of these studies (Homalitas et al., 2014; Maffei-Almodovar et al., 2017; Matthews et al,. 2014; Nigro-Bruzzi et al., 2010; Nosik et al., 2013; Sarokoff et al., 2004). Nearly half (n=14) of the 35 studies provided exact participant age, eight studies provided a range, and 12 did not report trainee age. Of the studies that reported participants' exact age, trainees averaged 33.26 years of age (n = 46 trainees, range 20-70). All studies focused on the training of a specific group: nine studies trained parents (35 trainees), four studies trained teachers (11 trainees), four studies trained direct care staff (12 trainees), four studies trained teaching assistants (nine trainees), two studies trained university students (30 trainees), two studies trained adults with autism (nine trainees), one study trained non-licensed instructors (13 trainees), one study trained caregiver (seven trainees), one study trained high school students (four trainees), and three studies did not report participant occupation (three trainees). Of the trainees, 23 studies reported the participants had no previous training in ABA, two reported having minimal training, two reported an unspecific amount of training, one study reported regular training, and four did not provide any information (see Table 2.4).

Learner Characteristics

The majority of studies (n = 27) included learner participants who received an intervention from a trainee (e.g. a child with autism who receives an intervention from a teacher who was trained with BST). These included a total of 91 learners with an average of 3.2 learners per study. Most of the learner participants had a developmental or intellectual disability, most commonly autism (n =37). One child had Fragile X syndrome, two children had Down syndrome, and 13 typically developing learners who exhibited problem behaviour (Drifke et al., 2017; Lafasakis; Lerman et al., 2015; Loughrey et al., 2014; Sawyer et al.,

2015). Participants also had a range of co-occuring diagnoses or characteristics, including food selectivity, language impairments, stereotypy, and aggressive behaviour. Of the 91 learners, 12 were female, 42 were male, and 37 learner genders were not reported. Learner age was reported for 68 participants and had a mean age of 6.3 years of age (range 2-39). Three of these 27 studies that featured BST delivery via a trainee did not report the total number of learner participants (Dart et al., 2017; Miller et al., 2014; Palmen et al., 2010).

Training Focus

The training interventions featured in the articles taught an average of 2.0 skills (range 1-7). For the articles that taught PECS (a picture-based communication system involving 6 phases), the training of each phase was counted as one skill (Homalitas et al., 2018; Rosales et al., 2009). Skills included discrete trial teaching (DTT), response interruption-redirection (RIRD), least-to-most prompting (LTMP), functional communication training (FCT), differential reinforcement of other behaviour (DRO), constant time delay, (CTD), naturalistic intervention, multiple stimulus without replacement preference assessment (MSWO), social skills (e.g., joining the conversation and asking for help), DTT, PEAK, reinforcement, pivot and/or re-direct use reinforcement, PECS 1-3A, incidental teaching (IT), activity schedule following, data analysis, ABC data, summary statement, treatment selection, differential reinforcement (DR), escape extinction (EXT), taste exposure, fading, mand training, guided compliance, non-contingent reinforcement (NCR), natural language paradigm, three-step prompting, differential reinforcement of alternative behaviour (DRA), delivering positive/negative reinforcement, functional analysis (FA), classroom management, error correction, graph analysis, errorless learning, and vocal shaping. These skills are described in Table 2.5

Table 2.5

Description of Procedures and Skills Taught in Behavioural Skills Training Studies

Skill or procedure	Description
Discrete trial training (DTT)	A systematic approach to teaching that breaks complex skills into smaller components. These smaller components are taught through brief, quick trials.
Promoting the Emergence of Advanced Knowledge (PEAK)	A packaged ABA assessment and curriculum to a variety of skills to learners with a focus on generalization and independence.
Reinforcement	The procedure of applying a consequence to a behaviour that will increase the likelihood of that behaviour occurring in the future. EX: Praising a student for a correct response (positive reinforcement) to promote the student providing correct responses in the future.
Picture exchange communication system (PECS)	A picture-based alternative/augmentative communication system aimed at teaching functional communication
Incidental teaching (IT)	A systematic form of teaching that structures the learning environment to create engaging activities that will capitalize on student interests and motivation and use those opportunities to target teaching new skills
Activity schedule following	Teaching a learner to follow a visual or textual schedule.
Data analysis	Reviewing learner data to determine if progress is being made to be able to make data-based treatment decisions.
ABC data collection	Observation data collection taken on the antecedent events, target behaviour, and consequence events (what occurs immediately after the target behaviour). ABC data collection is used to help determine the function of behaviour.
Summary report	Creating a written report including the key information from the session.
Treatment selection	Selecting the correct treatment plan based on the identified function of the target behaviour.
Differential reinforcement (DR)	The process of reinforcing a specific class of behaviours while withholding reinforcement for other classes of behaviours.
Escape extinction (EXT)	The withholding of reinforcement for a previously reinforced behaviour, resulting in reduction of that behaviour.

Taste exposure	A procedure for increasing food intake by gradually exposing the individual to small bites of food.
Fading	The process of reducing prompts when teaching a learner a new skills to decrease the level of assistance a learner needs to complete a task or activity.
Mand training	A form of training that uses prompting and reinforcement to teach a learner to request for an item or activity.
Guided compliance	Physical guidance to complete a task after the instruction has been refused.
Non-contingent reinforcement (NCR)	The delivery of reinforcement that is not contingent on the occurrence of a specific behaviour. Reinforcement is delivered on a fixed-time interval regardless of the learner's behaviour.
Natural language paradigm (NLP)	Now known as pivotal response training, is an approach to increase a child's motivation to learn and initiate communicate.
Three-step prompting	A teaching procedure that systematically moves through three increasingly intrusive prompts (verbal, model, physical) to assist an individual in preforming a task.
Differential reinforcement of alternative behaviour (DRA)	The delivery of reinforcement following the occurrence of a alternative behaviour to the target behaviour identified for reduction. EX: A child bites (target behaviour) his teacher in order to get the teacher's attention. If the student were to tap the teacher on the shoulder (alternative behaviour) the teacher would provide reinforcement (attention) to the child.
Functional analysis of behaviour (FBA)	The process of determining the function (or reason for) target behaviour. A functional analysis systematically alters environmental variables to determine the function of behaviour.
Classroom management	Applying ABA strategies in group format to promote positive behaviour change in classroom settings.
Error correction (EC)	A procedure an instructor implements when a learner exhibits an incorrect response.
Graph analysis	Visually analysing the graphic results of an instructional program or target behaviour reduction program to determine if behaviours are increasing, decreasing, or stabilized in order to make treatment decisions.
Errorless learning (EL)	A teaching procedure that is designed so that an individual does not make any errors when learning a new skill.
Vocal shaping	A systematic approach to teaching language that successively reinforcer closer approximations to the target word.

Several skills appeared in more than one article: DTT appeared nine times (Dart et al., 2017; Featherston et al., 2014; Lafasakis et al., 2007; Lerman et al., 2013; Nosik et al. 2013; 2017; Lerman et al. 2015; Sarokoff et al. 2004; Sarokoff et al., 2008; Subramaniam et al., 2017), IT four times (Featherston et al. 2014; Hsieh et al., 2011; Lerman et al., 2015; Loughrey et al. 2014), MSWO preference assessment four times (Gianoumis et al., 2012; Higgins et al., 2017; Loughrey et al., 2014; Sawyer et al., 2015), RIRD twice (Giles et al., 2018; Sawyer et al. 2017), and PECS twice (Homalitas et al., 2014; Rosales et al., 2009),

Setting and trainer

In almost a third of the studies (*n*=11) studies the training sessions took place at school (Belisle et al., 2016; Dart et al., 2017; Gianoumis et al., 2012;Graudin et al., 2012; Fetherston et al., 2014; Hogan et al., 2015; Lafasakis et al., 2007; Matthews et al., 2014; Miller et al., 2014; Sarokoff et al., 2008; Ward-Horner et al., 2012). In 6 studies training took place in the learner's home (Dogan et al., 2017; Drifke et al., 2016; Hsieh et al., 2011; Sarokoff et al., 2004; Sawyer et al., 2015; Seiverling et al., 2012), and in six studies the training was were performed in a clinic or treatment facility (Eid et al., 2017; Homlitas et al., 2014; Lerman et al., 2013; Lerman et al., 2015; Maffei-Almodovar et al., 2017; Palmen et al., 2010). Three studies were carried out at a university lab or clinic (Jenkins et al., 2016; Rosales et al., 2009; Sawyer et al., 2017) , three were in locations other than a school, clinic, or home (Higgins et al., 2017; Nosik et al., 2013; Shayne et al., 2013), one study did not report where the training took place (Giles et al., 2018), and four studies were conducted in a combination of different settings such as, home and clinics (Loughrey et al., 2014; Miles et al., 2009; Nigro-Bruzzi et al., 2010; Subramaniam et al., 2017).

Almost a third of the studies (*n*=11) did not report the level of training or experience of the individual providing the behavioural skills training to the trainees (Belisle et al., 2016; Gianoumis et al., 2012; Graudins et al., 2012; Lafasakis et al., 2007; Miller et al., 2014;

Nigro-Bruzzi et al., 2010; Nosik et al., 2013; Rosales et al., 2009; Shayne et al., 2013; Subramanian et al., 2017; Ward-Horner et al., 2012). In another third of the studies (n=12) the training was delivered by a university researcher (Dogan et al., 2017; Featherstone et al., 2014; Hogan et al., 2015; Homalitas et al., 2014; Lerman et al., 2013; Lerman et al., 2015; Maffei-Almodovar et al., 2017; Miles et al., 2009; Sarakoff et al., 2004; Sarakoff et al., 2008; Sawyer et al., 2017; Seiverling et al., 2012;). In one study the training was delivered by an experienced professional (Matthews et al., 2014). Graduate students provided the training in seven studies (Dart et al., 2017; Giles et al., 2018; Higgins et al., 2017; Hsieh et al., 2011; Jenkins et al., 2016; Loughrey et al., 2014; Sawyer et al., 2015). In three studies the training was delivered by a therapist whose level of experience was not specified (Drifke et al., 2017; Ed et al., 2017; Palmen et al., 2010).

Behavioural Skills Training Methods

Most studies provided the behavioural skills training portion in individual training sessions (*n*= 29), while five studies presented the training in a group format and one study using a combination of these two formats, as shown in Table 2.6. For the instruction component, six studies provided verbal instructions only, four provided written instruction only, and 24 provided both written and verbal instructions. A live model was used for 24 studies, while eight studies provided a video model, and two studies provided both a live and video model. Twenty one studies performed the rehearsal component in a role-play scenario with either the trainer or a confederate acting as the child, while 13 studies performed the rehearsal in-vivo with child participants. Almost all of the studies (*n*=30) provided verbal feedback, one study provided written feedback only, and three studies provided both written and verbal feedback.

Generalization was assessed in 17 studies and detailed in Table 2.6. Two studies assessed generalization to a new skill, five studies assessed generalization to a new learner,

four studies assessed generalization to a new setting and six studies assessed generalization in some combination of skill, child and setting. Maintenance was assessed in just over half of the studies (n=18) studies (whether the participant maintained the skill after a certain period of time after the study concluded). Maintenance as assessed on average 7.8 weeks following the training (range 1-52 weeks).

All studies reported inter-observer agreement (IOA) for trainee performance of the ABA procedure taught. IOA was collected for an average of 43.56% (range 15-100%) of training trials within the study. All studies except for one collected IOA data on at least 20% of trials (Palmen, et al., 2010). Mean IOA on trainee performance was 94% (range 83-100%). Procedural integrity was assessed for a third of the studies (n=13), with a mean integrity score of 99.4% (range 96-100).

Table 2.6

Components of Behavioural Skills Training and Research Design Included in Each Study

Authors	Instruction		Model		Rehearsal		Feedback		Training format		Generalization	Maintenance	Procedural Integrity	Social Validity
	Written	Verbal	Live	Video	Role Play	In-vivo	Written	Verbal	Ind.	Group				
Giles et al. (2018)	✓	✓	✓		✓			✓		✓	X	X	X	✓
Sawyer et al. (2017)	✓	✓	✓		✓			✓		✓	X	X	✓	X
Dogan et al. (2017)	✓	✓	✓		✓			✓	✓		learner	✓	✓	✓
Subramaniam et al. (2017)	✓	✓	✓		✓			✓	✓		setting learner	✓	✓	✓
Belisle et al. (2016)	✓	✓	✓			✓		✓	✓		X	✓	X	X
Sawyer et al. (2015)	✓	✓	✓		✓			✓	✓		learner	X	✓	✓
Homlitas et al. (2014)	✓	✓	✓		✓			✓	✓		setting learner	✓	✓	X
Featherston et al. (2014)		✓		✓		✓		✓	✓		learner	X	X	✓
Matthews et al. (2014)		✓	✓			✓		✓	✓		X	X	✓	X
Lerman, et al. (2013)	✓	✓	✓		✓			✓	✓		learner setting	X	X	✓
Shayne et al. (2013)		✓	✓		✓			✓		✓	X	✓	✓	✓
Graudins et al. (2012)		✓		✓		✓		✓	✓		learner	X	✓	✓
Seiverling et al. (2012)		✓	✓			✓		✓	✓		X	✓	X	✓
Hsieh et al (2011)	✓	✓	✓			✓		✓	✓		learner	✓	✓	X
Nigro-Bruzzi et al. (2010)	✓	✓		✓	✓			✓	✓		skill	X	X	X
Rosales et al. (2009)	✓	✓	✓	✓	✓			✓	✓		X	✓	X	X
Miles et al. (2009)	✓	✓	✓			✓		✓	✓		X	✓	✓	X

Sarokoff et al. (2008)	✓	✓	✓			✓		✓	✓		X	X	X	✓
Lafasakis et al. (2007)	✓	✓	✓			✓		✓	✓		X	X	X	X
Sarokoff et al. (2004)	✓	✓		✓		✓		✓	✓		X	X	X	X
Hogan et al. (2015)	✓	✓	✓			✓		✓	✓		X	X	X	X
Lerman et al. (2015)	✓	✓	✓		✓			✓	✓		X	X	X	✓
Eid et al. (2017)	✓	✓	✓		✓			✓	✓		X	✓	X	✓
Higgins et al. (2017)	✓			✓	✓		✓	✓	✓		X	✓	X	✓
Drifke et al. (2017)	✓		✓			✓		✓	✓		skill	X	X	X
Jenkins et al. (2016)	✓			✓	✓		✓		✓		setting	✓	✓	✓
Miller et al. (2014)	✓	✓	✓		✓			✓	✓	✓	learner setting	✓	X	✓
Gianoumis et al. (2012)	✓	✓	✓			✓		✓	✓		skill	X	X	✓
Ward-Horner et al. (2012)	✓	✓		✓	✓		✓	✓	✓		setting	X	✓	✓
Nosik et al. (2013)		✓	✓		✓			✓	✓		learner setting	✓	X	X
Palmen et al. (2010)	✓	✓		✓	✓		✓	✓		✓	skill	X	X	✓
Maffei-Almodovar et al. (2017)	✓		✓		✓			✓	✓		setting	✓	X	✓
Dart et al. (2017)	✓	✓	✓		✓			✓	✓		X	X	X	X
Loughrey et al. (2014)	✓	✓	✓	✓	✓			✓		✓	learner setting	✓	✓	✓

Trainee Outcomes

In the majority of studies, learner outcomes were assessed using a component checklist. A task analysis of each skill was either created by the researchers or adapted from previous research for use in their study and included each necessary step in correctly implementing the skill. The experimenters would score the learner's performance using the checklist to determine the amount of steps implemented correctly. The correct number of steps implemented was then divided by the total number of steps to yield a percentage score. For example, if there were 10 steps for a particular skill and the trainee performed eight out of the 10 steps correction, the researcher would divide eight by 10 to yield a score of 80% accuracy.

Majority of the studies (n=24) assessed trainee outcomes in-vivo. Seven studies assessed trainee outcomes in role-play scenarios (Jenkins et al., 2016; Maffei-Almovodar et al., 2017; Miller et al., 2014; Nosik et al., 2013; Rosales et al., 2009; Sawyer et al., 2017; Shayne et al., 2013). while three studies assessed outcomes combination of role-play and in-vivo settings (Gianoumis et al., 2012; Lerman et al., 2013; Subramaniam et al., 2017).

Almost all studies found immediate, positive results from using BST to teach trainees various ABA procedures. In most cases, participants met the mastery criteria for each skill within a short amount of time. For example, in one study all participants met mastery criteria (performing the skill with 90% accuracy) within 3-6 sessions (Subramaniam et al., 2017). Another study taught trainees two new skills, one of which was trained to mastery within one 10-minute session for all participants and the second skill was trained to mastery within either one or two 10-minute training sessions. Two component analysis were conducted and found that the full BST package was superior to individual components of the training alone (Drifke et al., 2017; Ward-Horner et al., 2012). Another study compared BST to computer-based instruction

and found that BST was superior to computer-based instruction. In many cases, the skills learned through BST maintained after the training, but not at the level of mastery. For example, Giles et al., (2018) used BST to train teachers to implement RIRD.

Learner Outcomes

Of the 27 studies that included learner participants (individual, most often children, who received an intervention from a trainee who underwent BST), 19 assessed learner outcomes and performance. These outcomes were included as secondary dependent variables in the studies. All but three graphed learner outcomes (Graudins et al., 2012; Palmen et al., 2010; Subramanuam et al., 2017). In most cases, learner outcomes were mixed. The most frequent reasons cited for lack of learner increases in skill acquisition was a lack of necessary prerequisite skills and the short duration of the study. For example, Gianoumis et al. (2012) included six learner participants, half of which demonstrated improvements in vocalizations, while half did not. Four out of the six participants demonstrated a decrease in maladaptive behaviours. It was suggested by the authors that the learners who did not exhibit increases in their vocalizations did not consistently produce prompted vocalizations prior to the intervention and, therefore, were missing the necessary prerequisite skills for the intervention. Two studies training trainees in DTT produces positive learner outcomes for all participants in correct responding for imitation skills and sight words (Lafasakis et al., 2007; Sarokoff et al., 2008). IOA was not collected on learner outcomes data in three of the 19 studies (Belisle et al., 2016; Miles et al., 2009; Palmen et al., 2010). Mean IOA for learner outcome data was 96% (range 82-100%). Due to the variability in skills taught through BST and the limited data available on learner outcomes, any additional patterns linking BST to improved client outcomes were unable to be identified.

Social Validity

Just over half of the studies (n=19) collected social validity data via a questionnaire. Most questionnaires were created by the authors to determine the acceptability of BST. Results from the questionnaires were very high in most cases, suggesting that the participants found BST to be an effective training model. The studies that used Likert-scale assessment tools found near ceiling results (i.e. scoring at or nearly at the highest score). For example, all mothers who were trained to implement treatment strategies for food selectivity rated the training as either 'excellent' or 'very good' (Seiverling et al., 2012). BST was found to be acceptable across all participant professional, including teachers, parents, and autistics adults.

Methodological Quality of Articles

The Evaluative Method was applied 36 times for 33 of the 34 articles (two articles had multiple studies; the group study was not included in this portion of the review). Articles were most commonly rated as Borderline Adequate (n=17), followed by Weak (n=9), and Strong (n=6), and shown in Figure 2.5. A detailed report of primary and secondary indicators can be found in Table 2.7.

On average, the studies had 4.4 out 6 primary indicators rated as High. Both independent and dependent variables scored well, with 32 and 34 studies rated High, respectively and the remaining studies rated as Acceptable. Visual analysis (n=30) and experimental control (n=32) also scored highly. Baseline ratings were High for 19 studies, Acceptable for two, and Unacceptable for nine. The most common reasons for baselines rating as Unacceptable was failure to include at least three data points or failure to establish a stable level.

The most frequent primary indicator that the studies did not meet the criteria for was participant characteristics. Most cases (n=24) failed to provide sufficient participant information

(age, gender, and trainer qualifications). An Unacceptable rating for a primary indicator prohibits a study from rating higher than Borderline Adequate, thus resulting in a large amount of studies obtaining this rating. If participant characteristics had been rated as High for the 24 studies, 21 ratings would have improved; an additional eight studies would have been rated as Strong, with the number of Weak and Borderline Adequate studies decreasing and the amount of Adequate and Borderline Strong studies increasing (see Figure 2.5).

The articles scored highly on secondary indicators with majority of the studies (n=26) including at least three secondary indicators with the remaining (n=10) scoring two secondary indicators. All but one study included sufficient IOA data (Palmen et al., 2010) and all but two studies included met the criteria for social validity (Dogan et al., 2017; Hsieh et al., 201). Most of the studies met the criteria for generalization and/or maintenance (n=27) and just over a third of studies included procedural integrity data (n=12). None of the studies included a Kappa score or used blind raters.

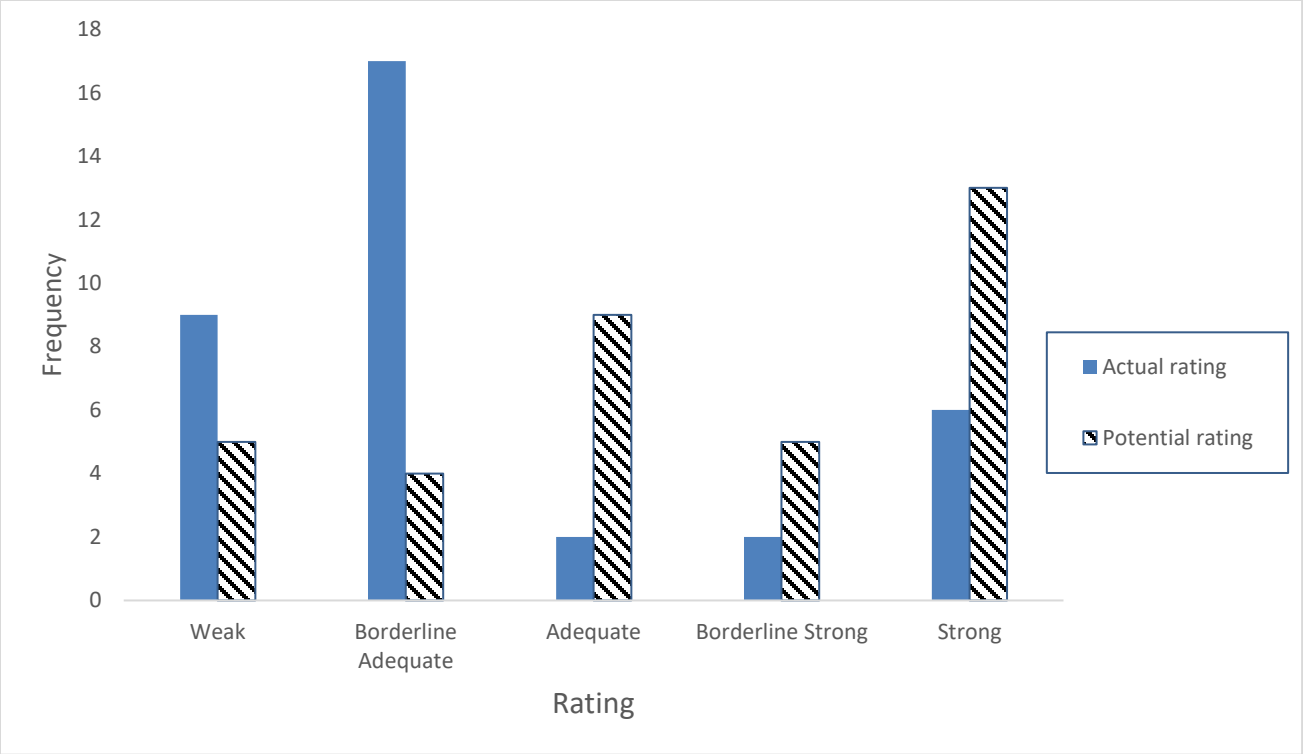


Figure 2.5. Evaluative method rating for behavioural skills training articles. Actual ratings reflect the scores assigned to the studies. Potential ratings reflect score had the studies included participant information to meet the criteria for High in that primary indicator.

Table 2.7

Results from The Evaluative Method

Author	T/C	Primary indicators						Secondary indicators						Rating
		PART	IV	DV	BL	VA	EC	IOA	KAP	BR	G/M	PI	SV	
Giles et al. (2018)	T, C	H	H	H	A	H	H	✓	X	X	X	X	✓	A
Sawyer et al. (2017)	T	H	H	H	U	U	H	✓	X	X	X	✓	X	W
Dogan et al. (2017)	T, C	H	H	H	H	H	H	✓	X	X	✓	✓	✓	S
Subramaniam et al. (2017)	T, C	U	H	H	A	H	H	✓	X	X	✓	✓	✓	BA
Belisle et al. (2016)	T, C	U	H	H	H	H	H	✓	X	X	✓	X	✓	BA
Sawyer et al. (2015)	T, C	H	H	H	A	A	H	✓	X	X	✓	✓	✓	A
Homlitas et al. (2014)	T	U	H	H	H	H	H	✓	X	X	✓	✓	✓	BA
Featherston et al. (2014) Experiment 1	T, C	U	A	H	H	H	H	✓	X	X	✓	X	✓	BA
Featherston et al. (2014) Experiment 2	T, C	U	A	H	A	H	H	✓	X	X	✓	X	✓	BA
Featherston et al. (2014) Experiment 3	T, C	U	A	H	U	A	A	✓	X	X	✓	X	✓	W
Lerman, et al. (2013)	T, C	H	H	H	H	H	H	✓	X	X	✓	X	✓	S
Shayne et al. (2013)	T	U	H	H	U	U	A	✓	X	X	✓	✓	✓	W
Graudins et al. (2012)	T, C	U	H	H	H	H	H	✓	X	X	✓	✓	✓	BA
Seiverling et al. (2012)	T, C	H	H	H	U	U	U	✓	X	X	✓	X	✓	W
Hsieh et al (2011)	T, C	H	H	H	H	H	H	✓	X	X	✓	✓	X	S
Nigro-Bruzzi et al. (2010)	T, C	U	A	H	H	H	H	✓	X	X	✓	X	✓	BA
Rosales et al. (2009)	T	U	H	H	U	H	H	✓	X	X	✓	X	✓	W
Miles et al. (2009)	T, C	U	H	H	H	H	H	✓	X	X	✓	✓	✓	BA
Sarokoff et al. (2008)	T, C	U	H	H	H	H	H	✓	X	X	X	X	✓	BA
Lafasakis et al. (2007)	T, C	U	H	H	H	H	H	✓	X	X	X	X	✓	BA
Sarokoff et al. (2004)	T	U	H	H	H	H	H	✓	X	X	X	X	✓	BA
Hogan et al. (2015)	T	U	H	H	U	H	H	✓	X	X	X	X	✓	W
Lerman et al. (2015) Experiment 1	T, C	U	H	H	A	H	H	✓	X	X	X	X	✓	BA

Lerman et al., (2015)	Experiment 2	T, C	U	H	H	H	H	H	✓	X	X	X	X	✓	BA
Eid et al. (2017)		T	H	H	A	H	H	H	✓	X	X	✓	X	✓	S
Higgins et al. (2017)		T	H	H	H	A	H	H	✓	X	X	✓	X	✓	BS
Drifke et al. (2017)		T, C	H	H	H	A	H	H	✓	X	X	✓	X	✓	BS
Jenkins et al. (2016)		T	H	H	H				✓	X	X	✓	✓	✓	
Miller et al. (2014)		T	U	H	H	U	H	H	✓	X	X	✓	X	✓	W
Gianoumis et al. (2012)		T, C	U	H	H	H	H	H	✓	X	X	✓	X	✓	BA
Ward-Horner et al. (2012)		T	U	H	H	H	H	H	✓	X	X	✓	✓	✓	
Nosik et al. (2013)		T	U	H	H	H	H	H	✓	X	X	✓	X	✓	BA
Palmen et al. (2010)		T, C	U	H	H	U	U	U	X	X	X	✓	X	✓	W
Maffei-Almodovar et al. (2017)		T	U	H	H	U	H	H	✓	X	X	✓	X	✓	W
Dart et al. (2017)		T	U	H	H	A	H	H	✓	X	X	X	X	✓	BA
Loughrey et al. (2014)		T, C	H	H	H	H	H	H	✓	X	X	✓	✓	✓	S

Notes: T/C Trainee/ Client, *PART* participant characteristics, *H* high, *A* acceptable, *U* unacceptable, *IV* independent variable, *DV* dependent variable, *BL* baseline condition, *VS* visual analysis, *EC* experimental control, *IOA* interobserver agreement, *KAP* Kappa, *BR* blind rater, *GM* generalization/maintenance, *PI* procedural integrity, *SV* social validity. *S* strong, *BS* borderline strong, *A* adequate, *BA* borderline adequate, *W* weak.

iii. Discussion

The results from the current BST literature indicate that it is a useful training package for training a variety of individuals to implement ABA strategies or procedures. Overall, trainees who received BST quickly learned how to accurately implement the ABA strategies. Positive learner outcomes were also demonstrated in the children and adults with autism who received an intervention from a trainee. Additionally, typically developing learners and those with additional disabilities also showed benefits of receiving interventions from those trained with BST. This suggests that BST is a useful training package for professionals working with a wide range of learners.

BST is growing in popularity, as evidenced by the increasing number of publications on this topic every year. Research articles are most often published in behaviour analytic journals and typically employ a multiple baseline across participants design. Most studies took place in a school, clinic, or the learner's home. A wide range of authors and research groups have studied BST. However, most reside in the United States of America.

Many of the studies included similar BST components; most included both written and verbal instructions. Most of studies presented a live model with the remaining using a video model. Approximately two-thirds of studies conducted the rehearsals in role-play scenarios, while the remaining third performed them in-vivo with learners. All but one study provided verbal feedback. There were relatively few component analysis or parametric analysis of BST. Additionally, only a third of studies collected data on procedural integrity. Additional research should be performed to address what components of the treatment are most effective and most likely to be implementer by the trainer over time.

Trainee participants were mostly female, and majority were parents/caregivers, teachers, or university students. Trainees typically worked with individuals with disabilities, most often autism. Most trainees had little or no pervious training in ABA. Few studies

specifically targeted entry-level ABA professionals (ABA tutors, RBTs, etc). No studies included in this review examined the use of BST with BCBAs. With BCBAs and RBTs being primary responsible for delivering interventions based on the principles of ABA, there appears to be a gap in the literature of using BST to train these professionals. Future studies should examine the efficacy of using BST to train BCBAs to implement new assessments or procedures.

Learner participants typically had a developmental delay or diagnosis (most often autism) and were primarily male. This is consistent with previous finding that found autism interventions studies have more male participants than female participants (Watkins, Zimmermann, & Poling, 2014). Few studies trained individuals who worked with typically developing children or children with other diagnosis or disorders (depression, anxiety, etc.). Future BST research could expand trainee participants to individuals who work with a wide variety of children.

Most trainees exhibited immediate and substantial increases in their ability to accurately implement the procedure targeted in the BST session. Maintenance and generalization results suggest that the skills learned through the training sessions would transfer to new skills and maintain over time. Learner outcomes, however, did not consistently display the same immediate changes in behavior. This was often attributed to the short timeframe with which the studies were conducted and the extended amount of time it takes for some children to acquire new skills. It is unclear if leaner performance would increase over time or if learner performance would be better for individuals whose instructors were trained using BST rather than another training format.

In most studies, training was delivered by a doctoral level researcher or a graduate student. In schools and clinics, often times new staff are trained by professionals whose level of qualification does not exceed a masters degree. Future studies should investigate the

efficacy of BST implemented by individuals without a doctoral degree to most closely reflect the training that most professionals typically receive. Additionally, targeting individuals who are responsible for training staff within their organization would help determine the acceptability and feasibility of incorporating BST into an organization's standard training programme.

BST has yet to be scaled and embedded into a semester-long university course. The effectiveness of the training model for one or a small number of trainees has been demonstrated. However, the feasibility of implementing BST to a large group or a class-wide setting should be further studied. Due to the time and resources required to conduct BST, the efficacy of group training should be further examined. Further, the articles in this review used BST to teach an average of two skills per study. Most individuals working with children with autism would need a full range of skills to be effective. Comprehensive trainings based on BST should be further explored. At this time, BST has never been scripted or manualised. The lack of a packaged, manualised BST programme causes the training format to be time consuming and may cause poor implementation.

The methodological evaluation found most (n=17) of the studies were of Borderline Adequate quality. However, there were enough studies with a Strong rating to establish BST as an evidence-based practice based on the criteria in the Evaluative Method. The most common reason for studies receiving Borderline Adequate rating as opposed to Strong rating was the lack of participant demographics reported. There would a have a much higher number of Strong articles had the researchers included a full description of the participations (age, gender, sociodemographic information, etc). The lack of participant information in behavior analytic research has previously been addressed by researchers (Li, Wallace, Ehrhardt, & Poling, 2017). Inclusion of such information into research studies is required by

some quality indicator tools, such as the Evaluative Method, and therefore would increase the number of studies qualifying as Strong.

Aside from participant demographics, most studies scored highly on the primary indicators, which include essential design elements: independent variable, dependent variable, baseline condition, visual analysis and experimental control. Primary indicators were rated as either High, Acceptable, or Unacceptable. The studies rated as High for an average of 4.4 out of 6 primary indicators. After participant demographics, baseline condition was the most common primary indicator to rate as Unacceptable. Researchers should be sure to collect sufficient number of baseline data points and establish stability before implementing the intervention.

Secondary indicators include design elements that are important, but not essential: interobserver agreement, Kappa, blind raters, fidelity, generalization or maintenance, and social validity. These indicators were rated as either evidenced or not evidenced. Majority (n=26) of studies showed evidence of at least three secondary indicators. Mostly commonly, interobserver agreement and social validity were evidenced in the studies. Generalization and/or maintenance was also reported in most studies (n=27) and procedural integrity was demonstrated in just over a third of studies. No studies included kappa calculations or used blind raters. Theses findings reflect the reach design elements most commonly used in ABA research and included in research methods textbooks. For example, one commonly used textbook includes sections on all secondary indicators except for Kappa and blind raters (Kennedy, 2005). Kappa statistics are only briefly mentioned as an alternative option, but not described in detail. Blind raters are not discussed at all, whereas, social validity and interobserver agreement have an entire chapters dedicated to them. This suggests that ABA professionals are not trained in including these design elements.

These finding of the methodological evaluation should be interpreted with caution. At this time, only the primary researcher has analysed the data from the methodological evaluation. A second researchers should review at least 50% of the articles and agreement in scores should be calculated and discussed in order to produce a final result. Additionally, the effectiveness of BST packages should be considered considering the publication bias that may occur with single-subject design research. Publication bias occurs when the published literature underrepresents studies that did not find the treatment effective. One study surveyed 243 single-case design researchers and found that researches were more likely to submit articles that had large effects (Shadish, Zelinsky, Vevea, & Kratochwill, 2016). Additionally, they were more likely to recommend the acceptance of manuscripts submitted for publication that had large effects. Some researchers even indicated they would not include cases in their manuscripts that had small effects. Therefore, the overwhelming positive outcomes shown in the BST articles included in this review may not be a reflection of the true effectiveness of BST and instead a reflection of the studies who had the most effective outcomes.

2.3.3 Pyramidal training approach

Another barrier to the dissemination and implementation of BST is that it can be very time consuming even for skilled professionals (Parsons, Rollyson, & Reid, 2013). BST requires demonstration, performance and feedback in addition to the verbal and written instructions that are typical of a traditional training program. One solution to address the lack of availability of professionals to deliver the training is to adopt a pyramidal training, or 'train-the-trainer' approach (Pence, Peter, & Tetreault, 2012). In this model, a highly trained professional (BCBA) trains a small group of individuals, (Tier 1 trainees) who then then train other individuals (Tier 2 trainees). Tier 2 trainees then provide direct care to individuals with disabilities (Tier 3 individuals).

Potential benefits of this approach include reduced demand for the highly qualified professional while simultaneously building the knowledge and skills of less experienced or qualified individuals (Demchak & Browder, 1990). It also enables the Tier 1 individuals to provide training to Tier 2 individuals in their place of employment with the materials they typically have available to them (Parsons, Rollyson & Reid, 2013; Pence, St. Peter & Tetreault, 2012; Van den Pol, Reid & Fuqua, 1983). A recent systemic review analysed 14 studies that implemented a pyramid training model (Andzik & Canella-Malone, 2017). The review found that pyramidal training was effective in improving staff performance in 100% of Tier 1 participants and 83% of Tier 2 participants.

In one application of a pyramidal training approach, Parsons, Rollyson and Reid (2013), used BST to train teachers (Tier 1 participants) to implement BST to train their own staff (Tier 2 participants) to use ABA procedures. Three groups of three teachers participated in a multiple probe design. The researchers created a checklist of the essential steps for delivering BST. Their ability to implement the essential steps of BST were assessed pre- and post-training, as well as on-the-job. The pre-training assessments were conducted in a role-play scenario, where an additional experimenter served as the "staff member". The teachers were asked to select an EBP they are currently competent in and to use BST to train a "staff member" to use as that EBP. During this phase, an observer recorded what percentage of items on the checklist the participant successfully completed. Average pre-training performance results for groups 1, 2 and 3 were 36%, 26%, and 29%. The teachers then attended 2, 1-hour BST sessions to learn how to implement BST. Post-training, average scores for correct implementation of BST for groups 1, 2 and 3 increased to 90%, 85%, and 95%, respectively. Following the training, the researchers visited the teachers at their schools and assessed their ability to use BST with one of their own staff members. 7 out of the 9 participants correctly implemented BST with 100% accuracy, while the remaining two

participants implemented it 88% accurately. This study therefore supports the use of BST to train new staff members to utilize this procedure to train their own staff. However, the teachers in this study already had mastery in the EBP they selected. More research needs to be conducted to determine if this procedure would be effective for training teachers without pre-existing knowledge of EBPs.

Some limitations in the pyramidal training literature is a lack of procedural integrity data and social validity data (Maffei-Almodovar, 2018). Additionally, only two study have sought to teach Tier 2 trainees more than one skill (Maffie-Almodovar, 2018; Pence, St. Peter & Teteault, 2012). Further, no studies assessed implementation fidelity of the Tier 1 trainer delivery training to Tier 2 trainees (Andzik & Canella-Malone, 2017). Without this data, it is difficult to attribute improved trainee performance to the training programme. Training delivered by Tier 1 trainers should be monitored and evaluated to ensure their training is responsible for the changes in trainee behaviour. Few studies have analysed the outcomes for Tier 3 individuals. Given that these individuals are the recipients of the interventions being taught, research should focus on determining whether there are improved outcomes for individuals whose instructors were trained via a pyramidal approach versus other training models. Finally, while pyramidal training has been used to teach a variety of skills (EBPs, safety procedures, and client-specific tasks), it has not been assessed for teaching more complex behavioral principles. Without a deep understanding of the science of ABA and the philosophy of behaviourism, it is unclear if the individuals trained in these EBPs will have the knowledge and skills to adapt the practices as needed with the individuals they serve. Without ongoing supervision and support from highly trained experts, it is unclear what the quality of services will be. Future research should explore the use of pyramidal training to teach complex topics to service providers. Studies could explore to what extent skills training

alone is enough and what level of training on the principles of behavior analysis is needed for more effective treatment.

Chapter 7 of this thesis seeks to address some of these limitations by implementing a pyramidal training approach to train parents of children with autism in Eastern Kazakhstan to deliver a short ABA training course to university students. Detailed procedural integrity and social validity data were collected to determine the feasibility and acceptability of the course. This approach was selected because employing international consultants in this region is very costly and therefore out of reach for many organizations in Kazakhstan, particularly organizations in rural areas. A pyramidal training approach could be an affordable and sustainable method for training professionals around the country to not only use EBPs, but how to effectively teach others to use EPBs.

3. Historical Context and Modern Policy and Practice for Individuals with Autism in Kazakhstan

3.1 History of Disability in the Soviet Union

Prior to the establishment of the Soviet Union, children with disabilities, including autism, in Central Asian countries were mainly cared for by private and philanthropic organizations (Lubovsky, 1974).[1] The Soviet Union assumed responsibility for the care and treatment of children with disabilities in 1919 and specialized institutions were created and expanded to accommodate a significantly larger number of children with disabilities. At this time, society viewed helping children with disabilities as the 'moral thing to do', with a view that the support provided would ultimately benefit the state by turning disabled children into productive members of society (Zamsky, 1980, p.325). Usefulness and work productivity were a priority.

The 1920s and 1930s saw rapid changes in the classification, treatment, and policies regarding children with disabilities. During this time, the term 'invalid' was officially adopted as the term classify children and adults with a physical or mental disability. The government did not intend the use of this term to convey negative connotations or the suggestion of reduced mental capacity; rather, the term stemmed from its previous use to describe war veterans who could no longer work due to injury from battle (Kalinnikova & Trygged, 2014). In 1921 the Soviet Union began dividing 'invalids' into three categories dependent upon their ability to contribute to the workforce; Category 3 was for those who no longer were capable of working and required constant care, Category 2 for those who lost capacity for standard work, but could do minor work, and Category 1 for those who require

[1] There is limited English-language information regarding autism in the Soviet Union or Kazakhstan. The only document identified is a brief report written by a Russian institution (Lebedinskaya & Nikolskaya, 1993). In this report, they claim to have diagnosed the first child with autism in Russia in 1978. They state that prior to this, children with autism were classified as schizophrenic. Due to the lack of information available specifically about autism, this thesis will discuss disabilities during this era more broadly.

supplementary social support to live independently (Phillips, 2009; Shilova, 2005). The individuals classified as 'invalids' would receive a subsidy from the government that was based upon which of the three categories the individual fell into. This categorization system continues to impact modern-day disability policy, as is discussed in later sections of this chapter (see Table 3.1).

Pedology[2], the science of child development and upbringing, quickly rose in popularity during the late 1920s and was widely accepted as the state-of-the-art treatment for children with disabilities (Kalinnikova & Trygged, 2014). The term pedology was first coined by American psychologist Oscar Chrisman in 1893. Pedology had early influences from G. Stanley Hall, a psychologist and first president of the American Psychological Association. It was brought to the Soviet Union by Aleksandr Nechaev who established an experimental pedological laboratory in 1901 (Minkova, 2012). The Soviets believed that with this method, children with various disabilities would be rehabilitated and enter the workforce. However, attitudes began to change as pedology failed to produce the expected results of fully transforming human nature. This failure was viewed by politicians as a poor reflection of the state was subsequently banned in 1936 (Grigorenko, 1998; Sirotkina & Smith, 2012). Politicians stated pedology was "pseudoscientific" and was "full of harmful, anti-Marxists tendencies" (Fradkin, 1990, p. 203). This ban included a burning of pedology texts, prohibition of practicing, a call for scientist to actively publish works criticizing pedology, and the deportation of Nechaev (Minkova, 2012). Coinciding with this ban, disability policy changed and children with disabilities began to be categorized as either 'educable' or 'non-educable.' Disabled children who were deemed 'educable' were sent to boarding schools,

[2] Pedology in this context is referring to the Soviet study of child development, not the study of soil in its natural environment.

while disabled children deemed 'non-educable' were sent to institutions (Kalinnikova & Trygged, 2014).

Coinciding with the decline of pedology was the development of a new field, '*defectology'*.[3] The term was first coined by L. S. Vygotsky in his 1929 work 'The Fundamentals of Defectology'. Defectology was created as a science to study the education of all children and adults with physical or mental disabilities and was widely adopted in the Soviet Union and satellite states, such as Kazakhstan (Lubovsky, 1974). Vygotsky established the core theoretical underpinnings of the field that persist today. He claimed that normal patterns of development are so robust that they persist in some ways in children with disabilities. Further, there are some characteristics that are common in all disabled children that are not present in typically developing children. Vygotsky classified these characteristics into two categories; primary and secondary deviations. Primary deviations referred to the primary defect in that child. Secondary deviations are offshoots of the primary defect. For example, a child's primary defect of visual impairment will lead to a secondary defect of an inability to move freely. The secondary defect impacts the child's ability to interact with their environment and impacts their overall development (Vygotsky, 1929). While defectology's roots more closely aligned with a social model of disability, the field quickly shifted to a medical model of disability. This new approach to defectology focused on children's deficits and viewed those deficits as problems that need to be corrected. This resulted in low expectations for children with disabilities, and a view that these children were 'poor investments' of resources (Kalinnikova & Trygged, 2014).

As time passed, the stigma surrounding disabilities grew as did efforts to hide disabled children. Children were instructed not to look at or discuss individuals with physical

[3] During the 1930s the western world shifted the language used to describe disability to more sensitive terms, such as *handicapped*. However, in the Soviet Union the term defectology was very well-established, had significant written works by prominent Soviet researchers, and was too politically-loaded to be changed (Grigorenko, 1998).

or mental impairments, leading to a culture of silence around disabilities (Murphy, Scheer, Murphy, & Mack, 1988). At the 1980 Moscow Olympics, when a Soviet representative was asked by a journalist if the Soviet Union would participate in the Paralympic Games, the representative quickly responded, stating that there are no invalids in the USSR! (Fefelov, 1986). Disability was not part of public consciousness or reported in the media (Grigorenko, 1998).

Just before the collapse of the Soviet Union in 1990, the USSR passed a new disability law that was adopted in several satellite sates, including Kazakhstan. This law presented a new definition of disability:

> "A disabled person is someone who needs social assistance or protection due to live activity limitations resulting from physiological or mental defects. Disability (life activity limitations) of a person consists of partial or full loss of his/her ability or possibility to care for him/herself, mobility, orientation, communication, self-control, and ability to work" (Seitenova & Becker, 2008, p. 8).

This law increased the provisions for individuals with disabilities and gave more rights and allowances for children. After the Soviet collapse, Kazakhstan gained its independence in 1991 and experienced a period of economic crisis, growth and stability. Kazakhstan made significant changes in disability law and signed key documents ensuring the rights of children with disabilities.

While the 1990 law provided guidance on the approach to disability, it did not provide a procedure for implementing the new law. Kazakhstan and other former republics, for the first time, were able to independently determine disability policy and procedures (Seitenova & Becker, 2008). This opportunity presented many challenges, as most countries lacked institutions representing individuals with a disability and expertise in disabilities. Due to a

lack of available information, it is unclear how each former satellite state established their procedures. However, it has been suggested that Kazakhstan adopted the Belarusian methodology (Seitenova & Becker, 2008). This led the way in establishing new determinants for the categorization of disability levels. In 1992, Kazakhstan published new criteria for three levels of disability (mild, moderate, and severe), continuing the soviet legacy of three levels (see Table 3.1). The new criteria were influenced by the International Classification of Function domains (health-related functioning classifications set by the World Health Organization) and were later adopted by Russia (Seitenova & Becker, 2008). With these developments, Kazakhstan now had a framework and legal requirements for caring for children with disabilities. However, to this day the country is struggling to provide timely evaluations, sufficient educational provisions, and adequate healthcare to these children.

Table 3.1

Classification of the Fundamental Body Functions Disorder and Limitations of Life Activity (UNICEF, 2014, p. 25)

Category one **Mild disability**	**Category two** **Moderate disability**	**Category three** **Severe disability**
Ability to self-services using aids.	Ability to self-service using auxiliary aids and / or with help of other persons.	Inability to self-service and total dependence on others.
Ability to learn in schools of general type, with observation of a special regime of the educational process and/or with the use of aids, and/or help of other persons.	Ability to learn only in special schools or by special programs at home.	Inability to learn.
A partial decrease in the ability to self-monitor own behaviour.	Ability to partially or completely control own behaviour with the help of other persons.	Inability to control own behaviour.

3.2 Barriers to Education

In 2002, Kazakhstan signed the Law on Social, Medical, and Pedagogical Correctional Support to Children with Special Needs, which states that every child has the right to an effective education. However, at present, there is a substantial lack of special education schools, trained professionals, and specialized interventions for children with disabilities to fulfil what is mandated by law (UNDP, 2013). Obtaining a diagnosis and receiving services is extremely difficult for families – autism is not well known or understood by the general the public and stigma remains.

At present, many higher education institutions in Kazakhstan have Departments of Defectology, which are the equivalent of Special Education Departments in Western countries. Defectologists are trained to work with children with disabilities. There are some cases where defectologists assessed and developed successful treatment plans for children with disabilities (Penn, 2005). However, it is most often the case that children in Kazakhstan are simply labelled, institutionalized and largely ignored (Penn, 2005).

As Kazakhstan's economy continues to grow, the government is dedicated towards entering the top 30 most developed countries (Adayeva & Satkaliyeva, 2016). In order to achieve the goals stated in the "Kazakh Way- 2050: Uniform purposes, uniform interests, uniform future" (Kazakhstan President's Message, 2015), improvements must be made to the education and quality of life for individuals with disabilities. Having signed into law the rights of all children, regardless of ability or disability to have an education, Kazakhstan has set forward in the direction of providing equal access to education (Law of Education, 2007; Law on Child's Rights, 2002; Law of Medical Support, 2002). Kazakhstan has also signed international documents dedicated to the promotion of education for all students (Convention on the Rights of the Child, 1994; UN Convention on the Rights of Persons with Disabilities, 1989). Despite these laws, most children with disabilities remain outside of the educational landscape. Common barriers to education can be categorized into three groups:

3.2.1 Issues with diagnosis and obtaining an education placement

In Kazakhstan, autism is mostly unknown among the general population (Tuganbekova, Rymhanova, & Madetova, 2015). To obtain a diagnosis, children are required to leave their family home and reside at the psychiatric hospital for one month to be evaluated and assessed. During this month-long stay the parents are only allowed brief visits. The majority of the facilities are blocked off from parents, so they are unaware of the conditions of the facilities. This experience is often very distressing for both parents and children. The ethical validity of this assessment has understandably been questioned (Markova & Sultanalieva, 2013). If families do not send their children to the psychiatric hospital, they are unable to receive a diagnosis or subsequent government support.

The children must then attend the Psychological Medical Pedagogical Commission (PMPC) in order to receive a placement in an educational setting (Markova & Sultanalieva, 2013). During these meetings, the PMPC may review the diagnostic reports, notes from other professionals who may have interacted with the child, interview the parents, or ask the child to perform some simple tasks. Based on the information available it is unclear if any standardized assessments or tools are used. The PMPC is comprised of specialists, most of whom have been trained in the traditional Soviet practices of medicalization and segregation of individuals with disabilities from the rest of society. There are constant conflicts between the PMPC and parents; parents feel that the PMCP does not spend enough time with their children, use outdated measures to assess autism and related functioning, do not value parent opinions and make decisions in a rapid manner without taking the time and care needed for an accurate assessment (see Chapter 4). PMPC can place a child in a mainstream school, a special education school with a remedial curriculum, a rehabilitative centre with no curriculum, remedial home instruction or deem the student ‘uneducable’ without any

educational provision. The decisions made by the PMCP have a significant impact on the child's educational trajectory and these decisions are typically not open to appeal (Markova & Sultanalieva, 2013).

3.2.2 Poor teacher training and professional development

Teachers need to have adequate skills to teach children with autism, emphasizing the need for high quality teacher training (Baimenova, Bekova, & Saule, 2015). In the 2010 State Program of Education Development, one of the main objectives was the training of highly qualified staff for the education sector (Republic of Kazakhstan, 2010). The plan also included the goal of increased specialists for inclusive education and working with children with disabilities.

Despite these goals and objectives, pre-service teacher training remains substandard and outdated. The theoretical model is not developed and training objectives and components to meet these objectives are not defined (Zholtayeva, Stambekova, Alipbayeva, & Yerzhanova, 2013). Materials and resources in higher education also tend to be renewed very slowly (Republic of Kazakhstan, 2010). It is reported that the training provided places little emphasis on teaching practical skills (OECD, 2009).

The professional development and continued training of current teachers is of equal concern. It is reported that 90% of teachers of children with disabilities have never received any specialized training (OECD, 2009). In-service training is not valued in Kazakhstan and is mostly unavailable. Schools often do not pay for in-service training and require teachers to use their own vacation time to attend training (OECD, 2009). There is an overall lack of training and specialists to provide it (OECD, 2009). Even when adequate training is provided, many professionals continue to employ traditional defectology methods, believe they know best, and refuse to engage with further professional development (Markova & Sultanalieva,

2013). Therefore, attitudes toward in-service training remain a significant barrier towards high quality education for children with disabilities.

In addition to pre- and in-service training, broader improvements need to be made to the profession of teaching. There is a significant lack of highly trained teachers (Duisembekova, 2013; OECD, 2009). Teacher salary and prestige is low, leading to a 'brain drain' in the education sector (Republic of Kazakhstan, 2010). The state plans to enhance the prestige of teaching and to increase spending on teacher training (Duisembekova, 2013). However, it is yet to be seen if these plans will make a positive impact.

3.2.3 Negative attitudes, stigma, and lack of awareness

Stigma and discrimination against individuals with disabilities is prevalent in Kazakhstan, leading to exclusion from fully participating in community, social, and educational settings (Open Society Institute, 2009). Teacher attitudes towards autism and inclusive education are mostly negative (Orynbassarova, 2017). This is worrisome, as teacher attitudes play a large role in educational outcomes for students with disabilities (Florian & Black-Hawkins, 2010; Rouse, 2008). Several reports have cited negative teacher attitudes in Kazakhstan as a major concern in the development of special education; as a consequence attitude change has been identified as a priority (UNDP, 2013; OECD, 2009; Republic of Kazakhstan, 2010; Open Society Institution, 2009; Statement of Kazakhstan, 2013).

Research findings suggest that negative teacher attitudes may due to a lack of knowledge, skills and training to work with children with disabilities (Ellins & Porter, 2005). One way to address poor teacher attitude is to provide pre- or in-service training (Campbell, Gilmora, Cuskelly, 2009; Male, 2011). Based on my experience from a previous fieldwork trip, young adults in Kazakhstan are more open to learning new teaching techniques and working with children with autism. This sets the stage for highly impactful, pre-service

training. Furthermore, the number of young teachers is also increasing by 2.6% each year (Republic of Kazakhstan, 2010), indicating that these young adults will represent a substantial portion of the workforce. Focusing training efforts on these young adults may be one strategy to produce long-term improvements in special education.

School administrators and directors share similar attitudes (Markova & Sultanalieva, 2013). Many have spent their entire careers in traditional education systems that segregate children with disabilities. Schools may be reluctant to accept a student with a disability for fear that their low grades will negatively impact their school ranking. Schools refuse to accept students stating that they do not have the necessary resources to teach them. There have even been reports of some mainstream schools accepting a student with a disability but then failing to provide support, increasing the likelihood that the student will fail and then arguing that this failure is evidence that children with disabilities do not belong in school (Markova & Sultanalieva, 2013).

3.3 Lack of Empirical Information

There are no statistics that report the number of children or adults with autism or an intellectual disability in Kazakhstan. The only national reports available describe the number of children with a ‘disability’. However, there are no clear guidelines for what defines ‘disability’. One report cited that there were 54,495 children with a disability in 2012, increasing to 69,111 in 2015 (Adayeva & Satkaliyeva, 2016). Another report cited 124,000 children with a disability in 2005, rising to 149,246 in 2012 (Republic of Kazakhstan, 2010). While the exact number is unclear, the occurrence of disability in children appears to be on the rise. Similar limitations are present for statistics on the number of children with disabilities enrolled in school, with the percentage of school-aged children with a disability in government reports ranging from 19.5% (Republic of Kazakhstan, 2010) up to 32% (Ministry Education, 2010). Additionally, these figures are not widely published and do not comply

with international standards regarding the definition, evaluation, and monitoring of disability. Without reliable data, it is uncertain how many children with autism are in Kazakhstan and what percentage of them receive an education.

3.4 Parent Advocacy in Kazakhstan

In the past two decades, NGOs have experienced steady growth in Kazakhstan. Part of this growth can be attributed to the reduced registration fee and the allowance of NGOs to receive state funds (Markova & Sultanalieva, 2013). As with many countries, parents have been the driving force behind this change (Rouse, Yakavets, & Kulakhmetova, 2014). There have been several grass-roots projects by parents, advocates and non-governmental organizations (NGOs) to raise awareness and increase access to services for children with autism, but these efforts have not been sufficiently recorded or disseminated. This lack of information makes coordination of efforts and services difficult and fails to capitalize on the reported success of some programmes (Rollen & Somerton, 2019).

There are a number of parent-led NGOs in Kazakhstan that have made impressive strides since their establishment. One such NGO, Ashyek Alem, was established to raise autism awareness and advocate for increased services. Within their first two years they participated in national roundtables, policy discussions, international conference, sent formal inquiries to parliament, held press conferences, appeared on talk show, fundraised, delivered parent training and joined a regional initiative (Markova & Sultanalieva, 2013). Parents of children with autism in Kazakhstan are likely to have the most knowledge of autism and are therefore uniquely qualified to advocate for their children (Zholtayeva, Stambekova, Alipbayeva, & Yerzhanova, 2013). The government has recognized the importance of the role of the parent in the management of their child's education (Republic of Kazakhstan, 2010).

3.5 The Advantages of Using Parents as Teachers in Higher Education Courses

Several studies have capitalized on the strengths and dedication of parents by embedding them in professional training courses as co-instructors, student participants, guest lecturers or as hosts for home visits (Collier, Keefe & Hirrel, 2015; Gilkerson, 1994; Hanson, Randall, & Colston, 1990). Co-instruction has been found to be a beneficial model of parent-professional collaboration for students (Gilkerson, 1994). For example, the Army Medical Command and the Uniformed Services University of the Health Sciences (USUHS) selected military parents of children with disabilities to identify competencies for working with children with autism, develop teaching curricula and serve as teachers for medical students learning to treat children with special needs and work with their families (Hanson et al., 1990). The involvement of parents in every step of the process for this project led to high rates of satisfaction for the parents, students and teachers, as reported in post-training interviews.

Another study embedded parents of children with autism into a one-semester (16 week) graduate level university course titled '*Assessment of Diverse Learners with Learning and Behavioral Exceptionalities'* (Collier et al., 2015). Fourteen volunteer parents presented their personal experiences of raising a child with a disability to 28 students. Afterwards, the students visited the families in their homes to see the volunteer parents with their children. The students completed pre- and post-questionnaires to assess self-perceptions of their communication and listening skills, level of understanding of the impact of raising a child with a disability, and their ability to emphasize with parents. Students also completed a reflection paper describing their experiences and how those experiences may influence their teaching. This study found that listening to mothers' narratives of parenting a child with autism led to students reporting a more positive attitude toward working with children with autism and more confidence communicating with parents.

Murry, Curran and Zellers (2008) utilized parents of children with disabilities as both co-instructors and learner participants in a semester-long college course for pre-service special education undergraduate students. One parent served as a co-instructor, while six additional parents participated in the course as learners alongside the undergraduate students. Pre- and post-course focus groups were conducted with 9 of the 27 students. The focus groups found a major shift in the pre-service teachers' confidence regarding their abilities to effectively instruct disabled students, as well as a greater recognition of the importance of parent/educator collaborations. Thus, courses that feature parental involvement may produce shifts in attitudes that are likely to have positive impact on the behavioural and academic adjustment of children with disabilities. Building strong parent-professional collaborations has been a key objective for the Department for Education and Skills (2004a, 2004b). Yet, most training courses do not directly prepare university students to communicate and work with parents. Embedding parents into training courses could address this gap in training and support the building of strong, parent-professional collaborations.

Research has also indicated that incorporating parents into training has additional benefits for the parents. McBride, Sharp, Hains and Whitehead (1995) suggested that by telling their stories with others, parents are able to reflect on their knowledge, experiences, and strengths which led to their child's achievements, bolstering their confidence. They also suggested that co-instruction provides parents with a new set of transferred skills, such as public speaking and networking, that would allow them to take on new roles in the future. These roles include advocacy, task force member, local, state and federal committee members, and conference presenters.

In order to act as a co-instructor for undergraduate and graduate university courses, it is necessary for parents to obtain a certain level of mastery of the content through attendance at specialized training sessions. Research has demonstrated that parents can learn how to

implement ABA strategies and that participating in a training program also gives parents a greater sense of empowerment and reduced stress (Minjarez, Mercier, Williams, & Harden, 2012). Additional research found that not only could parents learn how to implement ABA techniques, but that they can learn how to train others to use ABA using a pyramidal training or train-the-trainer model (see section 2.3.3 for more details on pyramid training; Symon, 2005).

To the best of my knowledge, only one study has utilized a pyramidal training approach in Kazakhstan. This study found that this model was successful for training individuals to implement and train others to provide social work services (Thorning, Shibusawa, Lukens, & Fang, 2012). Social work specialists from the United States social win collaborated with a Kazakh team to developed a 10-module curriculum on key topics in social work. The specialists then provided a five-day training for five Kazakh participants. The participants were professionals from varied backgrounds and no formal training in social work. Eight months later, the five Kazakh participants served as trainers and delivered the course in Kazakhstan to 19 participants, including physicians, university staff, nurses and dance therapists. The training sessions were recorded and evaluated based on a 5-point rating scales and scored an average of 4.8 (range from 3-5) on overall satisfaction of structure, content, delivery and instructor-participant interactions. This study suggests that a pyramidal approach shows promise as a feasible and acceptable model of training delivery in the Kazakhstan context.

4. Qualitative Study

Research Aim 1: Perform semi-structured interviews with mothers of children with autism in rural cities to gain insights into their perspectives on obtaining a diagnosis, finding an educational placement, and experiences stigma in the community. Explore the ways in which their experiences are the same or different compared to families who live in the two major cities, Almaty and Nur-Sultan.

Abstract

There is limited information available regarding children with developmental disabilities in Kazakhstan and even less information about children with autism. In this study, semi-structured interviews were conducted with twelve mothers of children with developmental disabilities (including autism) in East Kazakhstan, to examine their experience of receiving a diagnosis and accessing services. Using thematic analysis, three themes were identified from these data: (1) difficulties obtaining a diagnosis and educational placement, (2) insufficient or inappropriate educational placements, and (3) the need to work towards a better system. Results from this study demonstrate the need for modernized diagnostic procedures, qualified professionals, and better overall support for families of children with autism and developmental disabilities in Kazakhstan.

Many children with disabilities living in former Soviet countries face stigma, discrimination, and limited access to educational and healthcare provisions (UNICEF, 2014). One such country, Kazakhstan, is the ninth largest country in the world (11 times bigger than the UK) with a poulation of 18 million people, making it one of the least densely populated countries. Demographically, 63% of the population are ethnically Kazakh and 23% are ethnically Russian (Statistics Agency of the Republic of Kazakhstan, 2011). Kazakhstan was the last Soviet Republic to gain its independence, in 1991. Since that time, the country has been taking steps to promote the rights of individuals with disabilities. In 2002, Kazakhstan signed into the law that all children have a right to an education (Law on Child's Rights, 2002). However, a lack of trained teachers, specialists, and schools prevented this right from being upheld (UNICEF, 2014).

In Kazakhstan, most specialists working with children who have disabilities have been trained in the Soviet method of 'defectologia' which is translated to English as 'defectology'.[4] The term was first coined by L. S. Vygotsky in his 1929 work 'The Fundamentals of Defectology'. It was created as a science to study the education of all children and adults with physical or mental disabilities and was widely adopted in the Soviet Union and satellite states, such as Kazakhstan (Lubovsky, 1974). While defectology's roots more closely aligned with a social model of disability, the field quickly shifted to a medical model of disability, whereby the focus was on children's deficits, or 'defects', needing to be corrected. This continues to be the primary approach taken for training specialists to work with children with disabilities in Kazakhstan (Florian & Becirevic, 2011). Furthermore, 90%

[4] During the 1930s the western world shifted the language used to describe disability to more sensitive terms, such as, *handicapped*. However, in the Soviet Union the term defectology was too well-established, had significant written works by prominent Soviet researchers, and was too politically-loaded to be changed (Grigorenko, 1998).

of teachers of children with disabilities in Kazakhstan have had no specialized training or their training is outdated (OECD, 2009). The 2010 State Program of Education Development identified a goal of increasing the number of specialists working in inclusive education, suggesting that the government is aware of the need for improvement in this regard.

In Kazakhstan, very little is known about autism (Tuganbekova, Rymhanova, & Madetova, 2015). Parent advocacy groups have been the driving force behind awareness raising (Rouse, Yakavets, & Kulkhmetova, 2014). One such group participated in national roundtables, policy discussions, international conferences, sent formal inquiries to parliament, held press conferences, appeared on talk shows, fundraised, delivered parent training and joined a regional initiative within their first two years of operation (Markova & Sultanalieva, 2013). Despite these achievments, awareness is still lacking. In 2003 the National Centre for Correctional Pedagogy (NCCP) reported that there were only 77 autistic children in the country. This number grew to 2,000 in 2017, suggesting that there is growing recognition of autism. However, even based on these figures, given that the population of Kazakhstan is 18 million, this gives an autism prevalence rate of 1 in 9,000, which is substantially below the estimated global rate of 1 in 160 (Elsabbagh et al., 2012; WHO, 2013). The strong implication is that autism, despite increasing awareness, is still under-diagnosed in Kazakhstan.

Current healthcare policy in Kazakhstan states that a child can only be diagnosed with autism by a psychiatrist at age four after an extended hospital stay (An, Chan, & Botagoz, 2018). It should be noted that the tools and protocols used in Kazakhstan to diagnose autism and intellectual disability remain unclear as there is no guidance from the government on this issue. Without a regulated and systemic approach to assessment and diagnosis, it is possible that the few children diagnosed with autism are labelled inaccurately. It is, therefore, important to exert caution when researching autism in Kazakhstan. Nevertheless, after

receiving an autism diagnosis, children are categorized into three levels depending on their level of independence. Those placed in Category 1 have a 'mild' disability, Category 2 have a 'moderate' disability, while those in Category 3 have a 'severe' disability (UNICEF, 2014). The criteria for assignment to each category are based upon the psychiatrist's perceptions of the child's ability to learn, take care of themselves, and control their own behaviour, as described in Table 3.1. After receiving the diagnosis and being placed in one fo the three categories, the children receive a 'certificate of disability' which entitles families to receive a government subsidy. The amount varies depending on the child's age and disability category. The certificate also gives the parents the opportunity to attend the psycho-medical and pedagogical commission (PMPC). The PMPC meets with the families, observes the child, reviews diagnostic documents, and makes the final decision on the allocation of educational provision to the child. The child's allocation may vary between placement in a special school, a rehabilitation centre, home schooling, or, in the worst case, the child may be deemed 'uneducable' and given nothing (Markova & Sultanalieva, 2013).

To date, there is little empirical information regarding the experience of raising a child with autism in Kazakhstan. To my knowledge, there is only one qualitative study on the perspectives of mothers of autistic children on support and services for autistic children in Kazakhstan (An et al., 2018). This research included two focus groups in the main cities of Almaty and Nur-Sultan and the researchers worked with nine and eight parents from each city, respectively. The parents in this study reported their children as having a diagnosis of autism, although it was unclear if this diagnosis was confirmed. The results from the focus groups highlighted the delayed detection of autism in these children, a lack of understanding of the needs of autistic children in healthcare facilities, the limited support and availability of special and mainstream education, feelings of isolation and stigma, and an overall lack of

social support. As this work took place in the two largest cities in Kazakhstan, the availability of services or experiences of autism outside of the major urban areas remains unexamined.

The aim of the present study was to explore the experiences of mothers of children with developmental disabilities (including autism) who live in a small town in a remote area of East Kazakhstan with limited access to specialist and services. This is the first paper to examine this topic using in-depth individual interviews and will be the first to focus on a remote geographical location in Kazakhstan, where access to diagnosis and support may be even more limited than in urban areas. The interviews sought to investigate the mothers' experience of obtaining a diagnosis and receiving an educational placement, their hopes for their child's future, and their perspectives on autism. It was predicted that, in line with rural-urban disparities in other parts of the world, mothers in the current sample would face additional struggles relative to the mothers interviewed in earlier work (An et al., 2018).

4.2 Methods

4.2.1 Participants

Pilot Stage. A convenience sample of three mothers were recruited from a local non-profit centre supporting families and children with disabilities (one further parent was invited to participate but declined). The mothers and their children attended the centre for two days a week, for parent support and social activities. The mothers reported that their children (one boy, two girls) all had a diagnosis of autism, limited speech and communication skills, and additional intellectual disability. The children's ages ranged from six to eleven years (M=8, SD=2.64). One child was Asian/Kazakh and two were White/Russian. All three children were classed in Category 2 (moderate disability; i.e., can learn, take care themselves, and control behaviour with assistance and special provisions).

Interview Stage. Nine mothers were recruited by the director of the local non-profit centre for children with disabilities. All of the mothers' children received individual or group

therapy at the centre. The director of the centre approached mothers in-person to explain the purpose of the study. The director asked mothers if they were interested, stressing that their participation would be voluntary and would have no impact on their child's services. In total, 11 mothers were invited and nine opted to participate. Their children's (six boys and three girls) ages ranged from three to eight years (M=5.1, SD=2.05). Due to inconsistencies in the diagnostic process in Kazakhstan, all parents of children diagnosed with autism or a broader developmental delay/disability were eligible to participate. The children were therefore diagnosed with autism (n = 5) or a developmental delay/disability (n = 4; note: one child diagnosed with developmental delay was deemed too young to receive a diagnosis of autism in Kazakhstan). All children had parent-reported speech and language delay. One child was diagnosed with additional motor impairment, apraxia, and attention deficit hyperactivity disorder. Another child also had a visual impairment. Three of the children were in Category 1 (mild disability; ability to learn, care for themselves, and control behaviour with minimal supports) and nine were in Category 2 (moderate disability). Additional information about the children is presented in Table 4.1.

Table 4.1

Child Characteristics of Mother Interviewees

ID	Gender	Age	Ethnicity	Diagnosis	Category
1	M	7	Russian	Autism, language delay	2 (moderate)
2	F	6	Kazakh	Autism, language delay	2 (moderate)
3	M	11	Russian	Autism, language delay	2 (moderate)
4	F	4.5	Kazakh	Autism, language delay	1 (mild)
5	M	5	Kazakh	Developmental delay, language delay	2 (moderate)
6	M	3	Asian	Communication and emotional disability, language delay	2 (moderate)
7	M	5	Kazakh	Developmental delay, language delay	2 (moderate)
8	M	8	Kazakh/Russian	Autism, language delay	1 (mild)
9	M	5	Russian	Developmental delay, ADHD, motor impairment, apraxia	2 (moderate)
10	F	6	Kazakh	Autism, language delay	1 (mild)
11	M	6	Kazakh	Autism, language delay	2 (moderate)
12	F	4.5	Russian	Autism, language delay	2 (moderate)

Note: *ADHD,* attention deficient hyperactive disorder.

4.2.2 Materials and Procedures

Ethical approval for this study was obtained through the University College London Institute of Education Research Ethics Committee. All mothers provided informed written consent to participate in the study.

Pilot interviews took place in a private room at the centre. Interviews were conducted by the first author, with her questions translated into Russian with the assistance of a certified interpreter, and were audio recorded. Each semi-structured interview lasted an average of 2 hours. The initial interview guides for the pilot interviews were broad and designed to be exploratory. They included five main categories: (1) access to education, (2) quality of school, (3) alternative educational options, (4) perceived value of education, and (5) community attitudes. Open-ended follow-up prompts were used, where appropriate. The results from these interviews were analysed and discussed by EM and JA. The interview guide was revised based on the pilot interview; questions from the pilot interviews that were confusing, not culturally appropriate or that yielded irrelevant information were removed, while questions relating to topics that emerged as being important during the pilot interviews were added. For example, the researcher initially was not aware of the role the PMPC played in assigning children their educational placement. After learning about the PMPC in the pilot interviews, specific questions regarding the PMPC were added to the interview guide for the interview stage.

The revised interview guide included questions and follow-up questions from four main categories: (1) diagnostic process and educational assessment (e.g. visiting the psychiatric hospital for diagnosis and attending the PMPC meeting for evaluation); (2) current educational placement (what private or publicly funded therapies or interventions their children are currently receiving); (3) views on the child's future, and (4) any general comments parents had on autism in Kazakhstan. Emphasis was shifted from away from the

quality of schools, as none of the children in the pilot interviews were attending school, and moved towards the diagnostic and educational placement procedures. In accordance with guidelines for conducting semi-structured interviewing, the interview guidelines were developed to allow for flexible dialogue (Kallio, Pietila, Johnson, & Docent, 2016). The interviews began with general rapport building and familiarization with the mother's child (their age, diagnosis, personality traits, etc.) before beginning the interview questions. The interviews concluded with an open question asking if there was anything else the mothers wanted to add.

The interview stage took place in the individual therapy rooms at the centre. The interviews were conducted by the primary researcher (EM) in Russian with the assistance of two translators, one of whom was a certified translator and the other a mother of a child with autism, both of whom were fluent in English and Russian. The translators were provided with interview guides and discussed the questions with the researcher beforehand. They were also given a glossary to review that included information on technical language (e.g., psychiatrist, psychologist) to prevent the incorrect usage of terminology. The mothers were made aware of the purpose of the interviews and written consent was obtained. The duration of the interviews ranged from 22 minutes to 47 minutes, with an average length of 30 minutes. The length of the interview was dependent on the willingness of the mother to provide detailed answers and the range of experiences the mothers had. Often, the mothers of older children had more experiences to discuss than mothers of younger children.

The researcher's questions and the participant's translated answers were transcribed verbatim by EM. One of the authors (EM) analysed the results from the three pilot stage interviews and nine interview stage. Interviews from both stages were included in the results and analysed using thematic analysis (Braun & Clarke, 2006). An inductive or 'bottom-up' approach was taken to the coding process, which involved creating codes based off of the

data instead of fitting the data into pre-determined codes. EM and an independent researcher familiarized themselves with the transcribed interviews, developed and refined codes, and identified final themes and sub themes. The independent researcher was outside the research team and is an educational practitioner undergoing postgraduate research training.

4.3 Results

Three themes were identified: (1) difficulties obtaining a diagnosis, (2) inappropriate and insufficient education, and (3) the need to work towards a better system (see Figure 4.1).

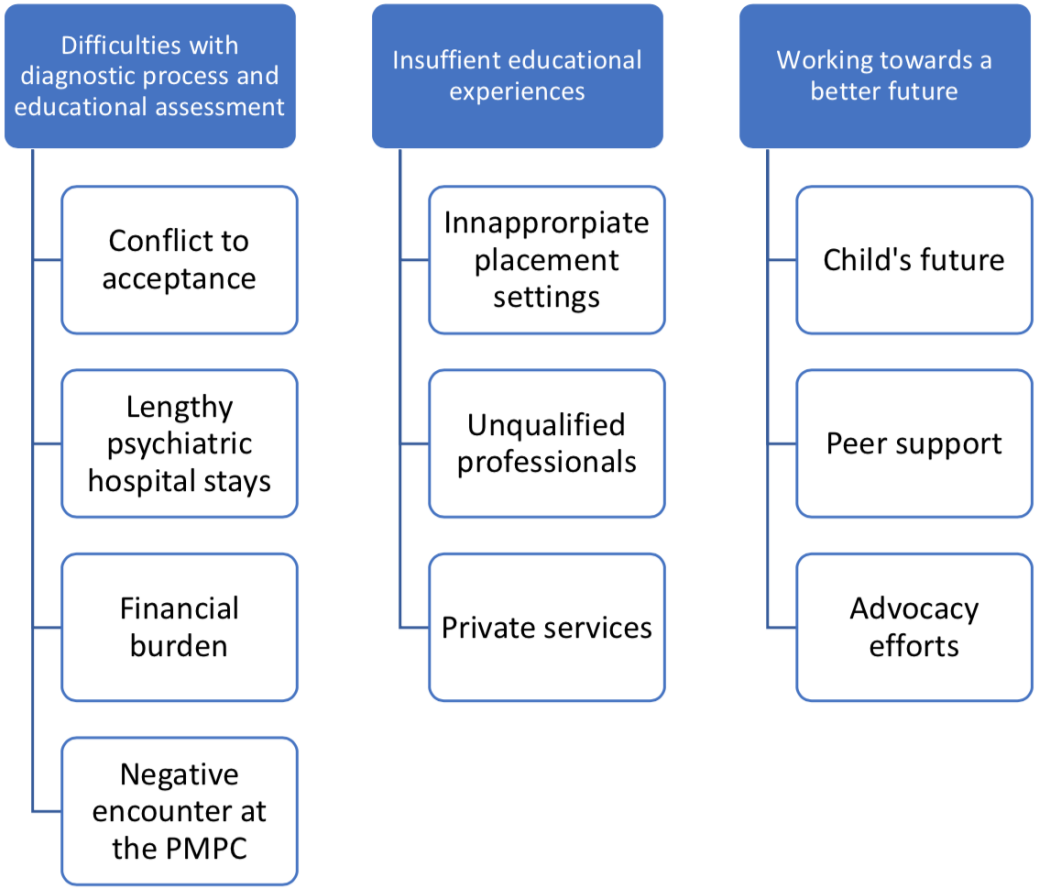


Figure 4.1 Mothers' experiences of autism: Themes and subthemes.

4.3.1 Theme 1: Difficulties obtaining a diagnosis

Mothers explained how the first obstacle in obtaining a diagnosis was moving from **shock and disbelief to acceptance** that their child was developing differently. The mothers reported first discovering that their child may have a developmental delay in one of two ways. Either the child was born with a neurological condition that was identified early by their pediatrician, or the parents began to notice signs of withdrawal and delay when their child was around 2 years of age. The mothers of the children without a neurological condition reported feeling: "shocked because she grew up normally until she was 2 years old. She was my girl. She wasn't like she is now. Until 2 she was like a normal child. Then, when she was 1 year and maybe 9 or 11 months she changed. Really changed." (Parent 10; P10).

Mothers described how this was a time of disbelief: "I was shocked and depressed and totally I did not know what to do and I was ready to die even. It was very heavy for me. It was difficult, it was a difficult time… I heard about autism, but I never paid attention to it. I thought it would never be my life. It can be anybody else's life, but not with me." (P12). At first, some mothers recalled being hesitant to pursue a diagnosis: "I cried at first. I did not want to go to the hospital. We couldn't accept that my son has autism." (P7). However, all parents reported that they moved towards acceptance: "My husband was ashamed that he had such a daughter who was quite different to other children….but now my husband says that he has the best girl in the world. Yes, really! Yes!" (P12).

The mothers further described the process of obtaining a diagnosis as lengthy and difficult: "We knew he had a disability at 1 month, but we had to wait until he was 4 to get the diagnosis…this is the process. A long process. It was hard for me." (P9). Another mother added: "It took us a lot of time. But, parents cannot quit because there are no other options." (P1). Many of them relayed how they understood the importance of early intervention and

did not want to wait until their child was 4 to begin this: “I think, we will have to wait a year [for intervention]. But, every day is very important for him.” (P11).

Many mothers reported travelling domestically and internationally to seek information to support their children. Given the lack of guidance offered to them in Kazakhstan, they resorted to pursuing interventions with little to no evidence-base: “When our son was eight months we found out something was wrong. Since then we have been trying to cure him with medical interventions and with massage. We traveled to another city in Kazakhstan to meet a Russian professor to learn his special technique.” (P11). This often came at a huge financial cost: “It was so expensive because we had to go to Russia to consult with doctors and specialists because we wanted a diagnosis. We attended dolphin therapy and it was so expensive. The conversion rate between Kazakh money and Russian money is so expensive.” (P8). While reflecting on this time in the interviews, many of the mothers cried.

The mothers recalled **lengthy psychiatric hospital stays** as a requirement to obtain a diagnosis. Some mothers reported successfully negotiating to reduce the requirement: “He was supposed to stay [for one month], but we spoke with the doctor and explained that it was not good for him. So every day he went to the doctor and stay there in the morning and I would take him home.” (P5). Another mother described her situation: “For 3 weeks my daughter would go for a half day because she has a problem with eating. She wouldn’t eat the hospital food and I wanted to make sure she was eating. Also, she was not potty trained.” (P4). She suggested that her daughter was permitted a reduced stay because the staff were unable to accommodate her dietary and toileting needs.

Other mothers explained how they were not able to negotiate a reduced residency: “I only visited my son for 2 hours a day, then I had to go home. For a month he was living there.” (P7). The mothers stated that during the visits they were not allowed into the main facility: “They are alone. The parents cannot go with them.” (P10). When asked what their

children were doing in the main facility, the responses varied: “I don’t know. Maybe they are watching cartoons.” (P1). Another mother suggested: “They do something. The psychologist examines her and they do some lessons. Massage.” (P10). Highly negative experiences were relayed during the interviews: “It was a little bit hard because my daughter cried every time we went to the hospital.” (P6). There were reports of “very aggressive children at the hospital” (P4) which left the mothers worried about their children’s stay.

After obtaining the certificate the families received their first form of financial support from the government, however the mothers reported feeling a continued **financial burden:** “Only my husband works, not me. It is so expensive to pay for specialists, massage, and everything.” (P4). In regards to the sum of the subsidy: “Yes, the government gives us some money, but it is not enough.” (P9). Comparing the subsidy amount to the cost of therapy at the centre: “I only get 70,000 KZT [from the government] and it costs 80,000 KZT to attend this centre for a half day. It costs the entire subsidy plus my own money.” (P11).

Once diagnosed, mothers stated that they were then required to visit the psycho-medical and pedagogical commission (PMPC) who: “makes the final decision where to direct these kids.” (P2). The mothers described predominately **negative experiences with the PMPC**: “every parent is afraid to go to such a committee.” (P1). Another mother said that upon hearing that she had to attend the PMPC for the first time that she “cried for a month” (P6) in anticipation based upon stories she heard from other mothers.

Mothers reported having to “apply for this committee two months in advance” and if you cannot make your appointment time “you should apply again and you will wait another 2 months.” (P1). The mothers stated the meetings were 30 minutes long and some: “believe 30 minutes is not enough time to make the right decision. It would be better if they communicated with the child for several meetings.” (P11). During the meetings, some mothers noted limited time is given to the child: “at this committee every kid has 5 – 10

minutes to show all his skills. And if for instance the kid is upset or hungry or doesn't want to show what he knows. They don't accept such a kind of behaviour. They state it as low mental abilities." (P1). One mother recalled that the committee: "only looked at my daughter for 1 second." (P4). The mothers also questioned the qualifications of the members of the PMPC and how up-to-date their knowledge was: "maybe 20 years ago they were well qualified, but not now. Maybe 20 or 30 years ago but not now." (P12).

Some mothers stated that members of the PMPC were "very rude" and held the belief "that the children are stupid and don't need an education." (P3). The meetings were reported as being very difficult for the mothers to endure: "It's terrible. This was very terrible because it is very difficult to hear that your child cannot learn anything. And you know what, I told them 'if you don't have any specialists that can teach her, that doesn't mean that my daughter can't learn. It means that we don't have any specialists who know how to work with her.'" (P12). Some of the mothers explained how they did not return to the committee: "I cried the first time, so my husband said 'I will do it!' So, only my husband goes there now." (P10). Only one mother reported a positive experience: "I suppose the main reason they've got such a good attitude towards us if that my daughter is calm. She does not scream or cry." (P3). However, she also stated had to: "stay in bed for two days after the meeting due to the stress." (P3).

The idea of appealing the decision proved to be comical to one respondent: "Ah, no. [laughs] because this is the government [laughs] it is impossible." (P12). However, "some parents try, but it's a low chance." (P1). Negotiating and reasoning with the PMPC was likened to: "speaking to a brick wall. It's useless." (P3). One mother explained how she had decided not to engage with the PNPC any further: "You know what, I am not even going to go there anymore because, I don't know why. What is the reason I should go there? They won't help me, they won't do anything. I can do it on my own." (P12).

4.3.2 Theme 2: Inappropriate and insufficient education and provisions

Due to the lack of services available, the mothers reported their children were often sent to **inappropriate classrooms or settings.** One mother reasoned**:**

> "Yes, yes we have the law that our child can get a free education. But, this law doesn't work because there are no opportunities for it. You see? There are no special classes for children with autism. There are no tutors who can work with such children. There is nothing for them. So we have the law and nothing for it and that is all." (P12).

It was reported that one child: "was sent to a kindergarten for blind children" however: "he has no problems with his vision." (P9). The mother explained that even though he was not blind: "it was a chance for him to attend kindergarten. There was nowhere else for him to go." After one month, "the head of the kindergarten told us to leave" because of his hyperactivity. Another mother recalled a similar negative situation: "We tried to go to a mainstream kindergarten. My daughter went there for two months and cried a lot. She would go for 3 hours a day. The psychologist at the kindergarten said that my daughter needed individual classes and she shouldn't be at the kindergarten." (P6). It was suggested: "that the main thing is the behaviour of autistic kids. They interfere with the educational process for the other kids" (P3) and this is why they are expelled.

Mothers reported that some children were sent to settings that resembled more of a day care provision: "in such rehabilitation centres the kids are there during the day, they've got some classes but it's not a kind of education. It's not." (P1). Several mothers who attended such facilities said they did not feel: "there is any progress there." (P5). One mother remembered: "after two weeks she protested, whining, shivering, hiding under the blanket." (P2). The mother visited the facility to assess the situation and found one adult in a room with

eight children: “Some of the children were very aggressive, so to avoid fights the adult had the children sitting alone in separate corners of the room….We had to quit.” (P2).

The mothers reported that there was a new government funded autism centre, however: “the waitlist is 2 years because there are so many children who need specialists.” (P4). The mothers felt that: “we do not have enough centres for such children. Especially government centres. Not all mothers have enough money to attend private centres. There is a government centre, but children can only attend this centre for 3 months. It is not enough.” (P6).

The mothers expressed concerns that: “the **professionals are not qualified** to work with children with disabilities.” (P3). One mother said: “In our opinion they’ve got rather low quality. As we can judge they’ve got almost no training at all.” (P1). The mothers commented on the lack of professional experience: “we attend a defectologists and speech pathologist and I feel like they are only practicing on my child and they don’t know how to actually teach such a child.” (P9). Overall, most mothers felt that there were not enough specialists or teachers to work with their children and the ones who were there were lacking the necessary qualifications.

In Kazakhstan, both Russian and Kazakh languages are spoken. Parents raised concerns as: “There are no autism experts who speak Kazakh. We cannot speak with them in our native language. It is a problem because the child has to have his lessons in Russian and then he gets back to his home and his parents speak Kazakh.” (P7). One mother identified this as the reason they had to change her son’s name: “There was a Russian caretaker who took care of him and that is where he got his name. It’s a Russian name. It was a Kazakh name, but then we change it because he got used to the Russian name.” (P5).

The mothers expressed mixed views concerning the perceived attitudes of teachers towards their children. According to one mother: “They don’t want to work with autistic

children. They have only very low expectations. They don't like such active children. They just want to give them food and sit there." (P10). One mother suggested that the older teachers: "do not want to learn anything new. It is difficult for them to change their mind." (P12). The mothers expressed a fondness for the young tutors: "I think the tutors who work with children with autism are heroes." (P12). However, another mother noted: "the young girls have no knowledge." (P7).

Due to the absence of an appropriate, public education with qualified teachers, mothers often sought out **private services** and specialists:

> "I went to Nur-Sultan[5] for one month. Tuition was 180,000 KZT. I rented an apartment, about 200,000 KZT. So it was about half a million KZT ($1,300, about half the median annual income for a Kazakh family) for 1 month. But it was worth everything. Thank God I went because she learned ABA[6] and they helped me. She made good progress with only 1 month of ABA." (P10).

A private centre was opened by two mothers of children with autism, prompting one mother to state "she is a great person for opening this centre." (P8). Nearly all of the mothers reported that their child attends the centre five days a week for three hours of group lessons and this is the only consistent therapy or education they receive. One mother organized additional services: "I hired a person, a defectologist, who agreed to learn ABA. I paid for her course and some online training. Now she is still working with my daughter." (P12). Several mothers reported moving to access services: "we used to live in a village and there were no specialists in our village. I did not meet any children like my son. We moved to this city when he was 5 and my husband found a job." (P7).

[5] The capitol city in the Northern region of Kazakhstan.
[6] Treatments based on the science of Applied behaviour analysis (ABA) are commonly used with autistic children.

4.3.3 Theme 3: The need to work towards a better system

When discussing their **child's future**, mixed reactions were given, from: "I don't want to think about the future" (P5) to "it's the only thing I think of" (P8). Some mothers expressed concerns: "I am worried about what will happen to my child when my husband and I are gone" (P3). Others were more optimistic:

> "I don't know, but you know what? Every day I am happy when I hear her say a new word or do a new skill. You know, when you are told that your child is not able to learn anything, and now I see it is not true. That she can learn new skills. Every day, one by one. I am happy. I am really happy. I don't know what she will do. Maybe she will swim. Maybe she will play the piano. She is just crazy about the swimming pool and about music. Maybe it will be her future and it will be my future." (P12).

The mothers expressed a desire for their children to become independent and happy: "You see I don't need her to be an economist or business woman, I don't need that at all. I need to see her happy. I want to see that she is not afraid of the world. And that she can communicate. That is very important." (P2). The mothers noted the importance of education: "If he could have a quality education. He would have a future." (P1).

All of the mothers reported the benefits of **peer support**: "I am fine because I communicate with other parents of autistic children." (P6). Some felt: "it is a big help for me to talk to other parents" (P5) and that "it helps to share our experiences." (P8). One mother reflected on her time at the psychiatric hospital and the rapport she built with other mothers: "I met five different mothers there who had the same diagnosis. We stayed and waited for our children together. We would talk and now we are very close friends." (P10). She continued: "everything that is free, I use. I tell all of my friends to use it too. I help families and tell them 'go there, you have rights! Go to some centres in Nur-Sultan.'"

Many parents reported being actively involved in **advocacy efforts**: “I want to change the situation and share my experience.” (P3). In regard to the government’s role, one parent stated: “Our problem is that the government does not hear us. Our problems, they do not hear them at all.” (P8). Many of the mothers believe the government should provide treatment but worry that it would come too late for their children: “The government should give us a good opportunity for treatment. Maybe the government medical insurance should pay [for treatment]. I don’t know. I don’t believe it will be until my daughter is grown up. We have to do it ourselves.” (P10). In the absence of government services, the education and interventions for their children falls upon the mothers’ shoulders: “It is so difficult to be a mother of an autistic kid because we have to be a housewife, we have to be a speech therapist. We have to be a doctor, psychologist, ABA specialist. We have to be everyone.” (P2).

When referring to navigating through the landscape of trying to find support for autism and intellectual disability, one mother described the situation as: “being trapped in a room with no doors. Just walls, walls, walls. All around you. You don’t know where you have to go. It looks like this, the situation in the whole of Kazakhstan.” (P12). This mother unsuccessfully tried to start an autism class one year ago, but stated: “I will try to organize this class again. I have to, I must do it because my daughter will become older. Think about it, if I want her to go to school, I have to do something for it. And I will.”

4.4 Discussion

The purpose of this study was to gain insights into the experiences of mothers of children with developmental disabilities (including autism) in East Kazakhstan. This was the first study to perform in-depth interviews and to examine the experiences of mothers living outside the two major urban cities. Three themes were identified from interview transcripts:

a) difficulties obtaining a diagnosis and receiving an assessment, b) inappropriate and insufficient education and provisions, and c) dedication to working towards a better future.

Many of the mothers' experienced shock and denial early in the diagnostic process, similar to parents in other parts of the world (Luong, Yoder, & Canham, 2009; Myers, Mackintoch, & Goin-Kochel, 2009). This shock may have been exacerbated by the overall lack of disability awareness in Kazakhstan and the high levels of stigma surrounding disability (Markova, & Sultanalieva, 2013). The mothers also experienced delays (often several years) in receiving a diagnosis, which is consistent with other regions of Kazakhstan (An et al., 2018) and across the world (e.g., Crane, Chester, Goddard, Henry, & Hill, 2016). However, unique to Kazakhstan is the policy that prevents children from receiving a diagnosis before age four, despite evidence that autism can be reliably diagnosed before the age of two years (Lord et al., 2006; Moore & Goodson, 2003). Adherence to outdated policies to the detriment of the patient health is an issue across Kazakhstan and particularly problematic for childhood neurological conditions (Duke et al., 2006).

The required one month residency at the psychiatric hospital and extended hospitalization is a legacy of the Soviet healthcare system that persists today (Rechel, Kennedy, McKee, & Rechel, 2011). These hospital visits place undue stress on families and there is little evidence supporting the need for such a lengthy, intensive observation period involving the separation of the child from their family. The 'gold standard' autism assessment tools, the Autism Diagnostic Interview-Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003) and the Autism Diagnostic Observation Schedule (ADOS; Lord, Ruttler, DiLavore, Risi, Gotham, & Bishop, 2012), can be administered and scored in 90-180 minutes and 30-60 minutes, respectively (Payakachat, Tilford, Kovacs, & Kuhlthau, 2012). Removing outdated policies and adopting modern assessment protocols may lessen the amount of stress the mothers and children experience as a result of the diagnostic process.

There were interesting contrasts between the results of this study and reports of mothers living in Kazakhstan's major cities, Nur-Sultan and Almaty (see An et al., 2018). An et al. (2018) reported that mothers living in the major cities reported primarily positive experiences of the PMPC, despite long wait times for appointments. In contrast, the mothers in this study found meetings with the PMPC to be stressful, emotional, and often devastating. The mothers in the larger cities appear to have better access to professionals and more positive experiences with the PMPC. This may reflect a regional disparity in the quality of professionals and access to services mandated by law. The inequality between rural and non-rural areas has been well documented in the literature outside of Kazakhstan (Mello, Urbano, Goldman & Hodapp, 2016; Murphy & Ruble, 2012). Lower pay, higher caseloads, and managing dual relationships (having additional relationships with clients and their families outside of the professional relationship) are characteristics of working in rural areas that may inhibit professionals from moving to rural locations (Pathman, Konrad, Dann & Koch, 2004; Pennington et al., 2009). Further research should be conducted to determine the extent to which these disparities may be occurring in Kazakhstan. In addition, much greater attention should be paid to the development of professionals and training programs to lessen the disparity and the use of incentives to draw professionals to rural areas (Murphy & Ruble, 2012).

Mothers reported that overall access to and quality of education and services was extremely poor, supporting previous reports that state the overall lack of special education provisions in the country (Duisembekova, 2013; OECD, 2009). Children were often placed in inappropriate settings with no additional supports, and subsequently expelled for their behaviour. The overall lack of trained professionals in these settings prevented children from accessing the services guaranteed to them by law. The need for practitioner training has been identified by independent organizations (UNICEF, 2014; OECD, 2009). During a qualitative

inquiry, teachers reported a desire to have specialized training, but none is available (UNCIEF, 2014). They stated that the government should do more to establish full training programs to prepare various professionals to work with children with disabilities. Additionally, several mothers noted that most professionals and materials are only available in Russian. Professionals fluent in Kazakh, classrooms and materials in Kazakh should be made available to include families who speak Kazakh at home. Additionally, due to the lack of schools and government-funded facilities, mothers frequently sought private services, many of which lack an evidence-base (e.g., massage, dolphin therapy). This may represent a lack of accurate, up-to-date information on intervention and support for children with autism and developmental delay available to families in Kazakhstan.

The government subsidy provided to the children and their families in Kazakhstan is based on age and membership into one of three categories of disability (mild, moderate or severe). Although the parents receive a subsidy comparable to other countries in the region (UNICEF, 2014) it is not enough to pay for private treatment. The cost of 15 hours of group therapy most mothers reported receiving exceeds maximum monthly subsidy amount. The subsidy also does not cover the cost of domestic or international travel. Families whose children are under the age of four must pay for everything using their personal funds. With a cost-benefit analysis suggesting that investing in early interventions may save money long term (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006), earlier and more substantial financial support from the government may alleviate some of the financial stress that families experience.

In the interviews the mothers exhibited a strong sense of comradery. Their efforts to establish services and advocate for awareness and provisions is in line with other efforts in Kazakhstan and around the globe (Markova & Sultanalieva, 2013; McCabe, 2007; Tilley, Dumbleton, & Bardsley, 2017). Parents have been the driving force of change, and if not for

the work of the mothers who founded the centre in East Kazakhstan, most of the children would not be receiving any type of education or treatment beyond babysitting. With the positive effect of social support for parents of recently diagnosed autistic children (Banach, Iudice, Conway, & Couse, 2010; Stuart & McGraw, 2009), support should be given to the further development of parent advocacy groups in Kazakhstan to enable them to help support more families of children with autism and related disorders.

This is one of the few studies on parental experiences of raising a child with autism in Kazakhstan, yet it is not without its limitations. First, all participants in this study had sought a diagnosis and successfully obtained government funding to receive services for their children. It is unknown how many families either do not seek a diagnosis due to stigma or who do not receive services due to the lengthy and difficult process of obtaining a diagnosis (OECD, 2009). A second limitation regards the use of interpreters for the interviews. The primary researcher, while familiar with Kazakh culture, is not native to Kazakhstan and therefore may have misinterpreted some sections of the interviews due to cultural differences. It is, therefore, possible that there were errors in translation that may skew the data. To attempt to minimize this, multiple interpreters were used when possible to provide further clarification. Finally, with the lack of updated diagnostic procedures, one cannot be confident in the specific diagnostic labels provided to the children (e.g., autism, developmental disability). Despite these limitations, the findings from this study provide insights into raising a child with autism or related developmental disability in East Kazakhstan. The results suggest a need for updated diagnostic processes and the development of new training programmes for teachers and specialists. The results also indicate the difficulties experienced by the mothers and their families. Future research should include parents living outside of the town, in even more remote locations, and include parents who have not sought a diagnosis (in order to identify additional barriers to diagnosis and intervention for children with autism)

5. Reflections from the field: An account of autism diagnosis, treatment, and training of professionals in Eastern Kazakhstan

Research Aim 2: Produce a reflective report, based on personal experiences in Kazakhstan, to provide context and discuss the current diagnostic process, professional training, and private services available in Eastern Kazakhstan.

Abstract

This chapter includes a reflective report summarizing information gathered during two fieldwork visits during 2019. This report drew on methods from focused ethnographic research; Interviews, on- site visits, participant observations, and field notes were taken. The results indicate that the diagnostic process is based on policies and procedures written 25 years ago and is mostly unstandardized. University students are not being prepared in up-to-date treatments. Many psychologists and defectologists are providing care with best intentions, but do not possess a deep understanding of interventions. Private centers specializing in autism are being created but lack strong clinical leadership. Recommendations: The diagnostics procedures need to be standardized and updated. Training of professionals needs to be brought in line with current international standards. Local specialists need to receive high levels of training in order to provide adequate interventions for children with autism or related disorders.

Little empirical information exists regarding the diagnosis and treatment of autism and other related developmental and intellectual disabilities in Kazakhstan. Chapter 3 of this thesis described the historical and political treatment of individuals with disabilities in Kazakhstan. However, the government documents and international reports reviewed in that chapter failed to adequately describe the current day to day life and struggles of individuals with autism and their families. The reports also failed to describe in detail the current standard of autism services and professional training. Chapter 4 sought to show the current experiences of families of children with autism or related disorders and provide their opinion of the current status of treatment and covering topics that are currently outside of the literature base. The present chapter includes a reflective report that draws from methods used in focused ethnography to identify information and experiences not otherwise represented in the existing literature. Additionally, this report provides context for the studies within this thesis.

An ethnography is the "description and interpretation of a culture or social group" (Holloway et al., 2010, p. 76). Ethnographic research can overcome the limitation of interview by data by combining multiple sources of information to produce a rich, descriptive account of a phenomenon (Reeves, Peller, Goldman, Kittu, 2013). Ethnographic research typically collects multiple types of data: participant observation, interviews, archival research, recording equipment, field notes, and reflective journals (Angrosino, 2007; Higginbottom, Pillay, & Boadu, 2013). Participant observation involves the researcher not only observing the sample participants, but actively engages and participates in everyday life (Dibley, 2011; Fetterman, 1998). The researcher acts as the primary data collection instrument in ethnographic research (Jackson, 1990; Marshall & Rossman, 2016). Because researchers come with their own cultural, background, experiences, and values, interpretation of the events occurring during the study could be subject to bias (Bernard, 2012). Researchers

must be aware of their own perspective and separate their own beliefs from the results (Dibley, 2011).

Traditionally, ethnographic studies are completed over the course of several years at do not have predetermined research questions (Mayan, 2009; Muecke, 1994). Focused ethnographies have emerged as a modification to traditional ethnographies (Mayan, 2009). Focused ethnographies consist of short-term projects (one-week to one-year) that investigate a specific topic or line of inquiry (White, 2009). They are most often employed in practice-based fields and are an effective method for capturing specific cultural practices, processes, and perspectives, while making practical use out of the information gathered (Cruz & Higginbottom, 2013; Magilvy, McMahon, Bachman, Roark, & Evenson, 1987).

The aim of this chapter is to produce a firsthand account of the current state of autism services in Eastern Kazakhstan. In particular, this chapter explores the current practices for preparing special education professionals, current diagnostic procedures, and current standard of treatment at a private clinic. The results of this report include my own personal observations, views, and reflections upon what is currently occurring in Kazakhstan, how this compares to internationals standards, and what improvements could be made.

5.1 Methods

The planning and execution of this chapter followed the five stages of performing field research identified by Singleton and Straits (2005): problem formation, gaining access, presenting oneself, gathering and recording information.

Problem formation. I used my experiences and knowledge from previous trips to Kazakhstan to aid in the creation of the research questions. Taking my own reflections and comparing it with the information present in the literature, I was able to identify discrepancies in what is currently presented in the literature, and gaps where critical

information is not represented. Based on these finding, I developed the line of inquiry of this chapter.

Selecting a setting: I had previously completed a volunteer project to a small town in Eastern Kazakhstan. During this trip, I cultivated key relationships with various groups and organizations. I selected the same site as for my doctoral research due to those existing relationships. Several years had elapsed between my original trip and the research trip, so many of the individuals I encountered I had not previously met. Despite the lack of existing relationship with many of the individuals, the few I did know indicated to the others that I was someone they could trust.

Gaining access: The primary gatekeeper to the individuals and locations in this chapter, as well as the other studies in this thesis, was the director of the local centre that provides educational and recreational services to children with autism and related developmental disabilities. Interactions were mostly informal, and I took every opportunity to engage with new people.

Presenting oneself: I presented myself as a researcher whose purpose was to perform studies and collect data for my doctoral thesis. Many individuals were curious of my presence, as there are not many international researchers that visit their town. I attempted to be as clear and transparent with the purpose of my visits and most individuals I encountered were eager to contribute.

Gathering and recording information: During spring 2019 I travelled to a city in Eastern Kazakhstan for two separate trips lasting three and six weeks each. During these trips, my transportation and accommodation were arranged by a group of mothers who run the local autism centre. During this visit, ad libitum observations were made at three sites; the local autism treatment centre, the local university responsible for training psychology and defectology students, and the psychiatric hospital where the children receive their diagnosis.

Photographs, videos, informal interviews, and field notes were obtained. Notes included information on the physical settings, characteristics of the individuals and their interactions with one another.

Of the three sites I visited, I first arrived and spent the most time at the local autism treatment centre. While at the centre, I spoke with the owners, the tutors, and the parents. I observed group and individual lessons. During these visits, photographs, videos, and notes were taken. These visits were often facilitated by a translator.

I took two trips to the local university. The head of the Department (HOD) of Defectology greeted me during both visits. The students in her department were participants in the main study of this thesis. The HOD spoke English and described her approach to training. She provided me with a tour of the facility and describe what each room was used for. While at the facility conducting pre- and post- tests for the main study, I observed the HOD providing individualized lessons to children with autism. Photographs and notes were taken during the visits.

I also had the opportunity to visit the psychiatric hospital where the children received their diagnosis. I had requested that the mothers who own the local centre contact the psychiatric hospital to arrange a visit. I was told it was unlikely that they would allow my visit. One evening between 9-10 PM I received a call notifying me that the psychologist agreed to speak with me, but that I would not be allowed to view the rooms where the children reside. The psychologist agreed to participate in an hour-long interview. She informed of the purpose of the interview and that the results would be included in this thesis and potential publications. Half-way through the interview, the psychologist requested and was granted permission to give me a tour of the facility. The psychologist spoke English, but a translator was available for additional support.

5.1.1 Information analysis and reporting

The information gathered was reviewed and reflected upon immediately after the trip, and then again three months later. The interview with the psychologist was later transcribed in English and analysed to identify the most relevant information. The results are presented in a narrative form, to present to the reader my experiences during my field trip, what it was like for me to be there, and what events I found to be interesting (Fetterman, 2010). In the discussion section, I reflect upon these results and provide opinions and suggestions base upon my background, prior knowledge of the Kazakhstan, and clinical experiences.

5.2 Results

5.2.1 Diagnostic process

The condition of the building housing the psychiatric hospital and its location next door to the drug and alcoholic rehabilitation centre provided some indication of the level of priority and importance that the government placed on this facility. The building was an old Soviet-block style building with crumbling paint and rubbish scattered across the ground (see Figures 5.1 and 5.2). When walking up the stairs to the second floor, the tiles of the steps cracked and moved around below my feet. Walking through the door, a sparse and tight waiting room for the parents was immediately in front of me and to my left was the locked door that led to the areas where the children are kept (see Figure 5.3).

We were greeted by the psychologist wearing a white lab coat and brought to her office. Her office was large and included a computer and desk. It comfortably sat three people and had toys and children's decorations throughout. The psychologist appeared to be excited for the opportunity to take part in the interview and was very forthcoming with her thoughts and opinions regarding the situation of autism in her country.

The interview began by obtaining background information from the psychologist. She stated that she had previously visited the United States and has received training and attended

conferences there. She said that she has a fairly good understanding of the American system and procedure for diagnosing autism and went on to explain how the Kazakhstan system and mentality is quite different. In Kazakhstan, she said that the mentality towards children with developmental disorders is quite harsh; they believed that that are an invalid and that is all, and that there is no point to try to teach them or rehabilitate them. The government only intends to give them a little money and push them to the side. She stated that the Ministry of Health does not acknowledge that these children can learn.

Figure 5.1. Entrance to psychiatric hospital.

Figure 5.2. Building holding the psychiatric hospital and drug and alcoholic rehabilitation centre.

Figure 5.3. Reception area of the psychiatric hospital.

The psychologist indicated that at the time of the interview there were 500 children in Eastern Kazakhstan with a diagnosis of autism, but she believed there are many more. She explained how many parents may have noticed something is out of the ordinary with their child but neglected to bring their child to the hospital for fear that the diagnosis would stigmatize them and prevent them from attending mainstream schools. She also struggled with government's influence over the number of diagnosis she is allowed to make in a given year. Last year she said she diagnosed 50 children with autism, then received a phone call from the government forbidding her from diagnosing any other children with autism due to a lack of financial resources to pay the families the subsidy. She also claimed that in recent years the government has restricted what diagnosis and classifications qualify for the government subsidy.

The psychologist then explained the standard diagnostic procedure. Typically, the parents are the first ones to notice symptoms. Often, paediatricians do not catch early signs of autism because they are not aware of the disorder. The psychologist said that this, in part, contributed to the late age of diagnosis. After noticing a delay, the parents bring the child to the psychiatric hospital for observation. The children can be brought at age two but cannot be diagnosed until age four and do not receive a government subsidy until this age. The psychologist stated that the diagnosis is not given until age four because of the regulations in place claim that development is not stable until that age. However, she hypothesizes that the government simply does not want to pay for earlier intervention programs.

Once the child is brought to the psychiatric hospital, they initially have a brief visit with the psychiatrist. The child then undergoes assessments with the psychologist, speech therapist, and defectologist. After each professional has met with the child, they individually write a report and recommendation and submit it to the psychiatrist. The psychiatrist reviews

the information and makes the formal diagnosis. In the event that a child has particularly complex needs, they will meet in person to discuss the child.

When asked specifically what the specialists did when they performed their assessments the psychologist indicated that no standardized assessment tools are used. She recalled that in Nur-Sultan (the country's capital) there was a training for the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2012), but that the training was not good and she did not feel prepared to administer the test. She also felt that the ADOS was too difficult, long, and expensive to realistically work in Kazakhstan. She stated that she has previously been trained and is proficient in administering the Verbal Behaviour Milestones and Assessment Placement Program (VB-MAPP), a language assessment commonly used by behaviour analysts to assess a young learner's current communicative level and guide treatment planning (Sundberg, 2010). However, the government forbid her from using this assessment and instead required her to use a state created checklist that was created over 25 years ago.

She further described her typical assessment: she observes how the child interacts with other children and how they engage in solitary play. She does some direct training with the child and uses stackable cups, shape and colour sorters, blocks, puzzles, and writing activities to determine the child's abilities. Then, based on the child's performances and their ability to complete the simple tasks, the psychologist uses her best judgement to determine what the child's diagnosis is. The psychologist recognized that this is not best practice for autism diagnosis procedures but indicated that it was the best she could do. She further explained that while she could perform the VB-MAPP and use the results to create a treatment plan, there would be no specialists that could carry out the plan and deliver the training to the child, so performing those assessments would be useless anyway.

At this point in the interview the psychologist was attempting to describe the facility and left to ask permission to give me a tour. When she stepped out of the room the translator (who is a mother of a child with autism) could be heard on the recording expressing her excitement, as no one has been allowed in that part of the facility before. The psychologist returned and provided us with white lab coats to put on before we were allowed to enter the rooms with the children. We exited her office and went through the locked door. There was a long narrow hallway with doors to rooms on each side. On the right there were several bedrooms that had metal cots with pillows on them. The cots lined the outer perimeter of the room, with the ends of each cot touching one another in order to squeeze as many cots into the small room as possible. There were no toys or personal items in the bedrooms or any pictures on the walls.

Opposite to the bedrooms was a small cafeteria, with a few tables and chairs. Further along the corridor the psychologist indicated that behind two of the doors there was an injection room and an electromagnetic therapy room. At the end of the hall were two rooms where the children were being held. One room was small and narrow, with large bulky shelving around the perimeter taking up approximately a third of the room. There were chairs in the room with thin cushions on them. The children had turned the chairs to face each other and pushed them together so they could lay on a soft surface and take a nap. Most of the children in the room were either laying on the chairs or laying on the floor. There were very few toys in this room and when asked about the toys the psychologist said that they had received donations of expensive toys and were afraid to give them to the children because the children might break them. There was one older woman sitting in the doorway blocking the children from walking in and out. When I spoke with the woman, I asked her how she was able to manage so many children and she said she just did what she could. She indicated that she has not received any training on how to care for or manage children with special needs. A

speech therapist was doing a puzzle in the back of the room with one child. The psychologist and speech therapist said that the child engaged high levels of aggression and she was observing them. When I asked how this one woman could handle the aggressive behaviours by herself with all of the other children in the room I was not provided with a concrete answer.

Next to this small room was a large room with more children and another older woman sat in the doorway. The room had a laminate flooring that was peeling up around the edges. In the far-left corner of the room a TV was mounted on the wall and was playing cartoons. Next to the TV there was a bench and there was a blanket on the floor. Most of the children were huddled by the TV and sitting on the blanket. The children appeared to be excited to have visitors, and when informed that I was American, they listed all of the English words they knew.

We returned to the psychologist's office to finish the interview. She described how the facility had 40 beds and could accommodation up to 40 children at any time. Typically, there were 2-3 children with autism there, but occasionally it would be up to 10. The other children in residence had mental or conduct disorders, such as schizophrenia, bipolar disorder, conduct disorder, frequently ran away from home, or were from poor families with unstable households or parents who were drug addicts. She explained how the facility used to be well staffed, but the government had reduced the number of staff to only two caregivers for 40 children. She stated how the staff struggled to meet the needs of the children who stayed there.

The remainder of the interview involved an informal discussion between myself, the psychologist and the translator who was also a mother of a child with autism. We discussed barriers to treatment and future directions for their town. The psychologist expressed frustration and anger with the governments lack of support. She indicated that she had written

several letters to the government to attempt to change the situation, but that the government did not listen. She believed that the parents must be the ones to make change. The mother agreed that if she wanted anything to improve she would have to do it herself. Additionally, we discussed the training of future professionals. The psychologist explained how there were few training opportunities and that they were very expensive. She stated that she had received previous training in ABA, but did not meet the requirement for BCBA exam. Further, she explained that at this point in her career she feels it is too late for her to go back and fulfil the requirements for the exam and it would be better if the young therapists were the ones to obtain this credential. We discussed, however, that most of the young girls could not afford the training and their English would not be of a high enough standard to complete the online courses from America. Additionally problematic is that if an individual were become certified, the psychologist hypothesized that they would likely want to live in a major city and not their town.

5.2.2 University training of pre-service specialists

Two visits to a local university were made. The university was in an affluent area of town and the department was in a large, updated building. The department had a large, open room with a conference table in the center and a projection screen. This room was the focal point and had several rooms that could be accessed through it. These rooms included the HOD's office, two small rooms for speech therapy and individual therapy, a playroom for therapy sessions, and a lecture room with desks. In addition to providing classes to university students, children with autism and related disability received direct therapy services from the HOD and other professionals at this site.

The playroom had various toys for the children to explore and interact with and was in good condition. The room was filled with a ball pit and had several interactive play stations around the room. There was a small fort-like structure that could fit one child and an

adult. The HOD said she would take the children in there and they would write down their fears on a piece of paper and then rip it up.

The individual therapy rooms were sparser, with less toys and interactive stations. One room looked like a small office with a computer, some toys, and adult sized table and chairs. The final therapy room was a small office for speech lessons with adult sized tables and chairs. The HOD said that she typically began the therapy lessons while the university students watched. Then she would step back and lets the university students take over the lessons. In the speech room she showed some metal instruments that she put in the children's mouths during their lessons and made a joke that they look like 'torture tools'.

During the tour one child was receiving therapy. The child had weights strapped to their wrist and ankles, with auditory integration therapy headsets strapped to their head. The therapist was leading the child by their hand and walking around the room. The child screamed and cried for approximately 50% of the time during the tour. Neither the therapist nor HOD indicated that the screaming or crying was in any way unusual or disconcerting.

The HOD utilized a combination of unsupported therapies during her treatments sessions and was resistant to learning new techniques. When discussing the topic of having an autistic student do simple imitation or following simple instructions ('do this', 'touch your ears'), the professor stated that it would take a miracle for an autistic person to be able to do such things. With these skills being the equivalent of a typically developing 1-2 year old, it was clear that the HOD had very low expectations for autistic students.

When speaking with the university students, they expressed that they did not have much experience working with children with autism or related disabilities, but that they had a strong interest and positive attitude towards learning new techniques. The students were neatly dressed and groomed, well mannered, and eager to engage with my questions. The

students demonstrated a high level of respect for the HOD and promptly followed all instructions given to them by her.

5.2.3 Private services available

During the field visits I made multiples trips each week to the private center for children with intellectual and developmental disabilities. The center was opened by two mothers of children with autism. The center of comprised of five therapy rooms, a sensory integration playroom, bathroom, and kitchen. The therapy rooms had small stools, chairs, and child-sized desks for the children to sit at. Some of the therapy rooms were large enough to facilitate group lessons, while others were small and used for individualized lessons. The facility was newly remodeled and in good condition with fresh paint, a computer, printer, and wireless internet. There was an abundance of toys, but limited educational materials (flash cards, math materials, etc). Since my visits, the center has moved to a new, larger facility.

Seven tutors were employed at the center aged between 20-23 years old. The tutors were all recent graduates from psychology or defectology programs. All but one tutor had no prior experience in working with children with autism. At the onset of their employment they received a two-week training course from a local psychologist. Another specialist visited the center to help give a structure to their lessons (first look at the schedules, then go do the activities). The tutors also received training from a sensory integration specialist. This specialist evaluated the children during an initial visit and gave weekly skype consultations to the tutors. The tutors demonstrated care and compassion for the children and did not yell or punish them in any way. When a child became aggressive towards them, the tutors remained calm and did not ‘retaliate’ against the child. Rather, they worked together to come up with solutions to better support the student. After therapy sessions, the tutors greeted the parents in the waiting room and provided them with a report of how their child did that day. The tutors

appeared to be friends and provided evidence of a supportive working environment; they helped each other, shared their snacks, and talked during their breaks.

Despite their best attempts, the tutors lacked the training and the skills necessary to design and implement more effective lessons. When provided with instructions or trainings on new techniques, the tutors were quick to learn and eager to implement new strategies. Their excitement and desire to develop their skills was palpable. They noted several times how it was their dream to have further training and how it was such a shame that no such training existed for them.

Typical treatment provided at this center was three hours a day, Monday – Friday. Treatment was provided in groups of up to 10 children. The children were split into two groups; one for the younger children aged 3-5 and one group for the older children, aged 6-11. There were 3-4 tutors supporting each group. Some children received individual therapy sessions at the center, but this was at an additional cost to the parents. The individual lessons were either given by the tutors employed at the center or outside specialists that used the facility. The individual lessons ranged from 30 minutes to one hour.

After observing many of their lessons and having extended conversations with the tutors and owners, I concluded that there was no educational curriculum for the group or individual lessons. The majority of the time was spent singing songs, dancing to music, or engaging in free play activities. The older children had some cooking classes and instruction on basic skills, such as ironing, however, there were no individual or group targets, goals, or systematic programs in place. Some children who received individual lessons had an 'ABA program' that was written by a specialist. However, most of these programs were very limited and were over 6 months old. Several of the older students appeared to be bored and were given unchallenging tasks. Many of the younger children lacked the pre-requisite skills to participating in group lessons (imitation skills, answering when their name is called,

following simple instructions). Therefore, the group lessons were only appropriate for the skill level of a few children. The children who were either too advanced or not advanced enough for the lessons often engaged in disruptive behaviors (running away, biting, screaming, crying, etc.).

The other specialists that provided private services at the center shared a similar situation. They showed a strong dedication to the children but lacked the in-depth training necessary for effective intervention. Many professionals had received several short courses on a variety of topics (sensory integration, speech therapy, ABA therapy, diagnosing, assessing, etc.), but most of these courses were one day or one-week courses.

5.3 Discussion

5.3.1 Diagnosis process

The interview and visit to the psychiatric hospital provided an opportunity to assess the discrepancies between the vague descriptions of the procedures in government documents and the reality of the diagnostic procedures. As far as I am aware, I am the first individual (aside from staff members) who has been granted access to tour the entire facility. After seeing the conditions of where the children are kept, I can understand why there is a closed-door policy in place. I imagine most parents would be upset with such conditions. The children were afforded no privacy or comforts and were restricted to very small areas. Given these conditions, the policies requiring children to stay for a month should be reconsidered. The facility appeared to serve dual purposes: to diagnose children with mental disorders and to serve as a social safety net for children who, due to family circumstances, have nowhere else to go. Separating and creating two separate policies, one for short-term housing for children needing support and one for children who need a diagnosis, would possibly allow the facility to better meet the needs of the children.

Additionally, child safety and well-being should be considered. Many of the children residing at the hospital engaged in aggressive behaviours (towards staff and other children). The lack of sufficient staff members on site resulted in children being in dangerous situations where injuries occurred. Though the children creatively rearranged furniture to provide them some comfort, the lack of stimulating materials, toys, or educational materials should also be considered. The benefit of removing the children from their families to reside at this facility was not, in any way, apparent to me. This potentially traumatic process should end.

It was clear that the current diagnostic procedures were not in line with international standards. Pediatricians should be trained in the use of early screening tools to help families identify symptoms as early as possible. Effective training of standardized assessment tools should also be provided to all professionals who are responsible for diagnosing children. Though the psychologist was aware of many assessments used in western countries, it was unclear if she was aware of the differences in the assessment she mentioned. Indeed, the ADOS is often identified as the 'gold standard' for the diagnosis of autism (Falkmer, Anderson, Falkmer, & Horlin, 2013), = there seemed to be confusion of the purpose of the VB-MAPP. While this assessment is often used in early intervention, this assessment does not diagnose autism, so it is unclear why the VB-MAPP would need to be done as part of the diagnostic process. Further training and professional development could help to clarify these kinds of misconceptions.

The overarching theme that emerged throughout the entire interview was the lack of governmental support and the failure of the government to allocate sufficient resources to this facility. Based on the psychologist's report, the government had not worked towards improving the situation for children with autism or related disorders, and instead made changes that further worsened the situation. Examples include limiting the number of autism diagnoses that were allowed to be given in a year and restricting what diagnoses qualify to

receive a subsidy. The psychologist was clear that she believed the government does not prioritize these children and needs to allocate significant funds and update regulations to help improve this process. Cultural attitudes and believes from the Soviet era seem to linger; individuals with disabilities are not full contributors to society and, therefore, receive limited support from the state.

It should be noted that despite the overall poor conditions and obstacles that are occurred, the psychologist demonstrated a deep concern and empathy for the children at the hospital. Despite the fact the she lacked the level of formalized training that many psychologists in the UK or United States have, she exhibited a desire for continued professional development. This is just one example of a professional who is making do with what they are given and is pushing towards a better future. Though the overall visit was disconcerting, her dedication and acknowledgement of the changes that need to happen provide some indication that things may change in the future.

5.3.2 University training of pre-service specialists

It was clear during the visit that the university staff did not possess up-to-date information regarding autism or its treatment. The use of outdated and ineffective treatments in the therapy rooms highlight this, particularly the use of auditory integration therapy (AIT). AIT is an intervention that is used to improve abnormal sound sensitivity in individuals with developmental and behavioural disorders, such as autism (Sinha, Silove, Hayen, & Williams, 2011). The efficacy of this treatment has been evaluated by professional governing bodies and independent researchers alike. Both the American Academy of Pediatrics and the American Speech-Language-Hearing Association have published statements on AIT. The American Academy of Pediatrics first published a report in 1998 clearly stating there is no evidence to support the treatment. They later reviewed the evidence in 2006 and once again concluded there was no research to support its use. The American Speech-Language-Hearing

Association similarly found no evidence of its effectiveness and even stated that its use by registered member may be in violation of their Code of Ethics. Independent researchers have conducted a variety of reviews, all finding little or no evidence of the efficacy of AIT (Dawson & Watling, 2000; Mudford & Cullen, 2005; Sinha, Silove, Wheeler, & Williams, 2006).

Simultaneously, the children were also receiving sensory integration therapy (SIT). SIT is based on the hypothesis that many of the abnormal behaviors exhibited by individuals with autism are due to a defect in the nervous system where sensory stimuli are processed (Schaaf & Miller, 2005). SIT is intended to provide specific sensory stimulation to improve the nervous system's ability to process and regulate sensory stimuli. It is believed that this improved sensory processing will result in a decreased in abnormal behaviors and an increase in adaptive behaviours and learning (Baraneck, 2002). However, evidence for SIT is weak and inconclusive. A systematic review of SIT found that there is no evidence to support its use as an intervention for children with autism (Lang et al., 2012).

The speech and language sessions were also of questionable quality. The metal instruments were particularly peculiar. After consulting with leading speech and language therapists in three different countries (USA, United Kingdom, and Romania), I failed to obtain any information on the use of these instruments. The purpose or efficacy of these instruments remains unclear.

The university treatment sessions provided an example of a professional providing therapy or using techniques from multiple fields. While inter-disciplinary treatment is often recommended for children with autism (Cox, 2012), usually that inter-disciplinary approach is delivered by a team of individuals who each have expertise in one field. Professionals, like speech pathologists, occupational therapists, and behaviour analysts, often receive master's degrees in their field, undergo supervised fieldwork experience and take certification exams

in order to become proficient in their chosen field. To be an expert in all these fields would seem unlikely. Even more problematic is that this individual is sampling from an array of unsupported treatments.

While using outdated and ineffective treatment, it became clearer why the head of department may have had such low expectations for children with autism. If a child received an ineffective treatment, it would be unlikely that they would make progress. If children are not making any progress and there is no acknowledgement that this may be due to a flawed intervention, the poor attitude of this individual towards the potential outcomes of children with autism is understandable. This is incredibly worrisome, given the level of influence this individual holds over the training of future professionals in the field of special education.

5.3.3 Private Services

The facilities at the center were the most up-to-date of all of the sites visited. The child sized furniture made it a much more comfortable environment for the children to learn. The children enjoyed playing with the toys and enjoyed the playroom. Parents overwhelmingly praised the centre and stated that since they have sent their children to the centre they have seen progress. Many stated they wished they could send their children to the center for more hours but lacked the financial means to do so. The achievements of parent groups in Kazakhstan have been commendable; parents are the driving force for change and the opening of this center provides services to children who otherwise would not receive support beyond a day care.

The tutors at the center were young and inexperienced. However, their level of patience and compassion was admirable. They were open to new ideas and techniques and were very quick to learn how to implement new teaching strategies. They were not tied to strict dogma or views on how to teach a child. They would quickly adapt when shown a newer, more effective technique. The development of autism services in Kazakhstan would

greatly benefit from maximizing the young professionals openness and enthusiasm for the field. Investing in and providing in depth training to these young professionals would create a new generation of knowledgeable, local special education leaders. Presently, such training does not exist in Kazakhstan.

Many of the private specialist who provided services at the centre shared the same levels of dedication to the children. They spoke fondly of the children and were constantly seeking more training. Often, they took time off of work and paid for the training courses themselves. This was very expensive and prevented them from receiving extended training (masters degrees, internationally recognized certification, etc.). The only contact most professionals had with BCBAs was through training programs, often sponsored by someone providing the training at a discounted rate. However, it appeared that these trainings frequently delivered the same, basic information on the ABA techniques. The redundancy in training can be a waste of resources and should be replaced by systematic, in depth training.

An additional unintended consequence of these short-term trainings is the Dunning-Krugger effect, which is a cognitive bias where people overestimate their knowledge or competency on a certain topic. This phenomenon appears to be currently occurring in Kazakhstan, where several professionals claim to be 'experts' but in reality have had very little training. The professionals attended several trainings on 'ABA', but all of the trainings only covered introductory material, leading the professionals to believe that the introductory material was the extent of the field and that they had learned everything there is to learn. Researchers have previously warned of the negative impacts that short-term training programmes may have for the field of ABA (Kelly et al., 2019).

There were several individuals who had enough ABA training to provide therapy that on the surface appears to be similar to interventions based on the principles of ABA. However, their lack of in-depth training on the principles of behaviour analysis caused the interventions

to be fundamentally flawed and often ineffective. For example, I observed a lesson by one specialist who had be taught to how to implement an error correction procedure. Error correction is used after the student makes a mistake. In this instance, the therapist was using the four-step error correction procedure (Forst & Bondy, 2002). The therapists asked the child to write the letter "A" and the child made a mistake and wrote the letter "O". The therapist then implemented the error correction procedure. The therapist simply stated 'no' and prompted the child to correctly write 'a'. Then the therapist distracted the child by asking the student to do something simple, like clapping their hands. After the student clapped their hands, the therapist re-presented the original instruction "write the letter 'A'. Doing this, the therapist correctly implemented the four-step error correction. Though the procedure was implemented accurately, it was not done analytically. Every time the student made an error, for the distractor the therapist would ask the child to clap their hands. Then every time the child was told no, the child clapped her hands even if no one instructed them to do so. The therapists failed to understand that the purpose of having the student clap their hands was to distract them or get their mind off of the original instruction. The specialist should have used a variety of distractors (look over there, touch your nose, give me the pencil). It was an understandable teaching mistake, one that is often made by novice therapist, but one that a well-trained analyst would have picked up on immediately.

Viewing staff profiles of other clinics around Kazakhstan indicated that similar patterns were occurring elsewhere; staff profiles included long lists of specialties (ABA, speech, sensory integration, son-rise, etc). The staff once again are received a little training in everything but lack an in-depth training in any of them. This seems to have led to a 'bag of tricks' approach, where the specialists would meet with a child and pull out different techniques or practices and use them in an unsystematic manner. Though not explicitly stated by the professionals, their approach mirrors the 'eclectic treatment' for autism. While

there is no one definition for eclectic treatments, it is often thought of as taking parts of several different approaches and applying them at the professional's discretion, to create an individualized, child-centered treatment plan. While this approach may sound appealing, there is a lack of evidence of its efficacy and flaws in its theoretical underpinnings. A comparison study found that after three years, children who received three years of early and intensive behavioural interventions scores significantly higher than children who received an eclectic treatment program (Howard, Stanislaw, Green, & Sparkman, & Cohen, 2014).

The importance of local experts cannot be understated. Having scientific knowledge as well as knowledge of the local customs and culture would place local specialists in a more favorable position than international specialists. Additionally, it is very expensive to pay for international specialists. Most of the BCBAs live in the United States of America where Medicaid (US health insurance for disabled people) is often responsible for funding ABA services. Medicaid rates vary per state, but can be as high as $125 an hour for BCBA services (Maglione, Kadiyala, Kress, Hastings, & O'Hanlon, 2017). Most at the centre visited in Kazakhstan struggle to afford $100 a month, therefore, treatment provided by BCBAs far too expensive most families.

5.3.4 Conclusion

This chapter should be interpreted with caution. The events described in this chapter were all observed through my own cultural lens, which may have misinterpreted some events. The recommendations presented in the discussion section are based upon my clinical training and experiences. Despite these limitations, this chapter provided detailed information not-otherwise available.

While some progress has been made, there are critical areas for improvement. The diagnostic process needs updating and the regulation of preventing a diagnosis before age four should be lifted. University training programs need to be re-evaluated and updated to

include the most recent scientific approaches to the treatment of autism and related disabilities. Specialisms (speech therapy, occupational therapy, behavior analysis, etc.) need to be developed to prevent generic autism specialists. Young professionals should be targeted develop the next generation of service providers and leaders. Finally, parent advocacy groups and NGOs should seek further collaboration to be as effective as possible. All of these improvements will be most effective if given full government support.

6. Manual Development

Research Aim 3: Develop a training manual, based on current best practices and sensitive to the cultural context of Kazakhstan, to train parents and university students to work with children with autism in schools using a train-the-trainer model approach.

The lack of training programs, specialists, and services in Kazakhstan provided the impetus for the main study, described in Chapter 7. In this study, a group of mothers of children with autism or related developmental disorders delivered a training programme to undergraduate and graduate students at a local university in Kazakhstan. Due to the mothers' limited knowledge and training in ABA, I created a systematic training manual for the mothers to follow during the programme. This chapter provides a description and rationale for the development of the training manuals for the main study.

6.1 Lack of Manualized Training Programmes

Although there is a significant number of free and commercial training materials available, none of the existing training materials met the needs of this study. Many of the video and audio training materials were only available in English and would therefore need to be translated prior to their use in Kazakhstan where Russian and Kazakh are spoken. Furthermore, translations of existing programmes developed and designed for Western populations would lack any needed adaptations to be sensitive to the Kazakhstan cultural context. Additionally, existing written training materials have not been designed with a focus on teaching skills. For example, Tarbox and Tarbox (2017) authored *Training Manual for Behaviour Technicians Working with Individuals with Autism*, but this manual is more similar to a practitioner textbook. It consists of detailed information about the content and specific information to teach behaviour technician, but does not include activities, instructor scripts, and does not incorporate behavioural skills training.

The Rubi Network training manual titled *Parent Training for Disruptive Behaviour* is a commercially available training manual (Bearss et al., 2013). It includes a parent workbook and a scripted instructor manual with activities and corresponding videos. However, this manual is intended for training parents of children with disruptive behaviour, not specifically AUTISM. While the Rubi Network manual includes some skills on the Registered Behavior

Technician task list, it does not cover several key skills, such as discrete trial training (see section 6.2.2 for description). This training programme is designed for typically developing children with disruptive behaviours, not specifically for children with autism. Because of this, the training programme does not include

For these reasons, none of the published manuals at this time were suitable for the purposes of this study. Therefore, training manuals were developed specifically for this research project. An instructor manual was created for the individual delivering the training. It consists of 11 scripted sessions with a corresponding PowerPoint presentation embedded with video examples. A student manual was created for individuals receiving the training. This manual includes readings for each of the 11 session, activity pages to complete in-class activities, and additional resources such as a glossary, sample data collection sheets, and fidelity checklists in the appendix.

6.2 Selection of ABA Skills to Include in the Manual

6.2.1 Selection criteria:

When designing the manuals, the content and focus of the training had to be considered. Content considered were ABA skills and procedures, theoretical underpinnings of behaviourism, experimental analysis of behaviour, and the principles of behaviour analysis. Due to previous complaints of teaching training in Kazakhstan being too theoretical (OECD, 2009), the manual focuses on *how* to teach and provides detailed descriptions of how to implement practical ABA skills. Only a brief introduction to the principles of ABA was included in the manuals. It was expected that the individuals participating in the treatment would be there due to an interest in helping individuals with disabilities, rather than an independent interest in the science of human behavior. Therefore, it was expected that the trainees would be more interested in learning practical skills to help those individuals than the science of human behaviour.

My own personal experiences delivering a two-day PECS and ABA training to over 1,500 professionals (psychologists, speech therapist, teachers, occupational therapists) also influenced the decision to base the training primarily on skills. Evaluations were completed at the conclusion of each training workshop. While most participants reported a positive experience with the training, many commented that the background information was too long and boring. Most preferred the skills-based sections of the training to the background sections on ABA. After receiving the full training, some attendees asked for information to learn more about behavior analysis and how to pursue graduate training. It is hypothesized that the current training will provide an overview to the trainees and will spark an interest in a few that may go on to pursue more in-depth training on behavior analysis.

This approach comes with limitations. Without a sophisticated understanding of the principles behind the procedures, the trainees may not be able to successfully adapt the procedures to those they work with. The interventions they seek to implement may not be effective due to their limited knowledge. A training course that focused more on the science of behavior analysis may prevent some of these issues and better prepare professionals to be independent practitioners. Future versions of this manual could be revised to include a greater amount of content on the science of behavior analysis.

The current version of the manual includes ten ABA teaching strategies were selected to be directly assessed during the study. The selection of these strategies was determined based on two primary factors:

(1) Inclusion on the Registered Behaviour Technician (RBT) Task List.

AND

(2) Identification by the National Clearinghouse on Autism Evidence and Practice (NCAEP) and National Professional Development Centre on Autism (NPDC) as evidenced-based practices.

The RBT task list was established by Behaviour Analyst Certification Board, the primary international accreditation body for behaviour analysts (BACB, 2020). RBTs are direct service providers who implement ABA therapy in 1-on-1 or group settings. They share a similar role, education level, and backgrounds to the university students and teachers who will be invited to participate in this programme. The task list was established by the BACB to include the core skills that are essential for direct service providers to have in order to deliver ABA therapy effectively. The task list is also meant to serve as a training curriculum for individuals new to the field of ABA. The task list contains 37 items that are categorized into six categories: Measurement, assessment, skill acquisition, behaviour reduction, documentation and reporting, and professional conduct and scope of practice (i.e. only working with populations or behaviours that the individual has received sufficient training in). The Task List is the basis for the content of the 40 hours training course and exam. Select procedures from the Task List are used during the Competency Assessment, where RBT candidates must demonstrate competence in performing the procedures.

The NCAEP is an extension of the National Professional Development Centre on autism (National Autism Center, 2009), which conducted a systematic literature review identifying 27 EBPs. Wong et al. (2013) used the NCPD standards to conduct a review of evidence-based practice for children, youth and adults with autism. The review assessed behavioural, developmental and/or educational interventions for participants from birth to 22 years of age with a diagnosis of AUTISM, pervasive developmental disorder (PDD), or high-functioning autism. Participants with co-occurring disorders were included in the review. The criteria for qualification as an EBP was:

1. At least two high quality experimental or quasi-experimental group designs conducted by at least two different researchers or research groups.

OR

2. At least five high quality single case design articles conducted by at least three different researchers or research groups, with at least 20 participants in each study.

OR

3. A combination of at least one high quality experimental or quasi-experimental group design article and at least three high quality single case design articles conducted by at least two different research groups.

The review analysed 456 articles and found 27 interventions that met the standards for EBPs. Of the 27 interventions, 16 were identified as behavioural interventions or based on the principles of ABA (see Chapter 2, Part 2). An additional six interventions have elements of ABA and are commonly used by BCBAs (naturalistic intervention, parent implemented intervention, peer-mediated instruction and intervention, self-management, visual supports, and technology-aided instruction and intervention). The remainder of the identified interventions, cognitive behavioural intervention, social narratives, social skills training, exercise, and structured play groups, are not explicitly based on the principles of ABA. One limitation of this review is that it was unable to calculate an effect size due to the inclusion of group and single-subject designs, as there is no agreement on the best practice for calculating an effect size for single-subject designs (Kratchowill et al., 2013). Despite the limitations, this review suggests that ABA strategies represent a large portion of EBPs for use with children and adolescence with autism.

Many of the ABA strategies identified as EBPs in this review are on the RBT Task lists. The overlapping items on the RBT Task List and procedures identified as an EBP in the review were identified as the most critical and fundamental skills to include in the manual. Table 6.1 lists the ABA strategies selected and indicates their inclusion on the RBT Task List or identification as an EBP in the review.

Table 6.1

Selected ABA Skills Included in the Main Study

Skills Selected	RBT Task List	Wong et al. (2009)
Data collection methods	Yes	No
Preference Assessment	Yes	Yes- included under reinforcement
Schedule of Reinforcement	Yes	Yes
Functional Behaviour Assessment	Yes	Yes
Prompting	Yes	Yes
Discrete Trial Training	Yes	Yes
Error Correction	Indirectly under discrete trial training	Indirectly under discrete trial training
Task Analysis	Yes	Yes
Chaining	Yes	
Mand Training	No	Yes- included under functional communication training
Token Economy	Yes	Yes- included under reinforcement

6.2.2 Selected ABA strategies:

The following is a description of the selected ABA strategies and the rationale behind their selection:

Data Collection: While directly listed in the RBT Task List, data collection is not explicitly listed in the Wong et al. (2013) report. ABA is a data-driven field, where practitioners are required to collect, graph, and analyse data. Behaviour analysts then use this information to make treatment decisions, in keeping with the scientist-practitioner model of psychology practice. The importance of data collection is highlighted in the RBT Task List, which dedicates an entire section to measurement. While not independently highlighted in the EBP report, data collection strategies would have been used by the researchers when implementing ABA strategies.

Preference Assessments: Preference assessments are used to identify what items or activities are most likely to be reinforcing to the child at that time. While there are many types of preference assessments, a paired stimulus preference assessment was selected for this manual because it is quick and relatively easy to use. To implement this strategy, an instructor presents two items to the child and gives the instruction, “take one; which one do you want; go for it”. The child then selects the desired item and the instructor records the selected item on a data collection sheet. Then, the instructor retrieves the item and re-presents a new combination of two items (either two new items or one of the previously presented items paired with a new item) to the child and repeats the instruction. The instructor repeats this process with different combinations of several items to determine which items are more and less preferable to the student.

Functional Behavior Assessment: Functional behaviour assessments (FBA) are completed to determine the function, or the reason, why a particular behaviour occurs. FBAs are frequently performed for challenging behaviours and the results are used to develop treatment plans (Fettig, 2013). There are several types of functional behaviour assessments, varying in complexity. For this manual, analogue assessments were selected because research shows they can be successfully implemented using BST training (Ward-Horner & Sturmey, 2012). To complete this assessment, an instructor observes an individual engaging in a problematic behaviour and records the events prior to, during, and after the behaviour. The data is analysed to determine the function. This is commonly called ABC data collection to reflect the recording of the antecedent events, behaviour and consequence.

Prompting: Prompting strategies include additional assistance given to the child to help them complete a skill. Common prompts include verbal, gestural, model, visual, and physical. The term prompt fading is used to describe the process of eliminating the prompt so the student can independently perform the task. Prompting procedure are an integral part of implementing many ABA strategies (Cox, 2013) and thus was given considerable attention in the training.

Discrete Trial Training: Discrete trial training procedures involve a one-to-one instruction approach to teach skills in a structured and systematic manner. Discrete trial training may be done at a table in a more structured manner or could be embedded in the natural environment. Inclusion on both lists and well as the frequent use in ABA practice constitutes its inclusion in the manualized training programme.

Error Correction: Error correction procedures involve systematically responding to student errors during lessons. Error correction procedures increase skill acquisition and decrease the future occurrence of errors (Smith, Mruzek, Wheat, & Hughes, 2006). While not independently listed, error correction is essential to effective discrete trial training and was therefore included in the programme.

Task Analysis: Task Analysis involves breaking down longer or complex behaviours, such as brushing your teeth, into smaller steps for the student to complete (see Figure 6.1). Task analyses are commonly taught using chaining procedures, described below (Fleury, 2013). Given the inclusion on the RBT Task List as well as in the Wong et al. (2013) report, task analysis was included.

Tooth brushing task analysis

1. **Put toothpaste on tooth brush**
2. **Wet tooth brush**
3. **Brush top teeth for 1 minute**
4. **Brush bottom teeth or 1 minute**
5. **Brush tongue for 30 seconds**
6. **Spit in sink**
7. **Rinse tooth brush**
8. **Put tooth brush away**

Figure 6.1. Sample task analysis for tooth brushing.

Chaining: Chaining procedure are used to help a children with autism or other developmental disorders complete a skill based on a task analysis. Instructors can select forwards or backwards chaining to teach the skill. Forwards chaining involves teaching the first step in the task analysis to mastery before moving on to the second step. For example, to teach a student to write the name 'Tom', the instructor would first teach the student to write the letter 'T' independently. Once the student could independently write 'T', the instructor would teach the student to write 'To'. Finally, the instructor would teach the student to write 'Tom'. Backwards chaining follows the same process but would first teach the student to write the letter 'm', followed by 'om' and finally 'Tom'. While not independently on either list, chaining was included due to its frequent use in combination with task analysis procedures.

Token Economy: Token economies for children with autism are systems designed to deliver tokens for positive behaviours that can be exchanged for reinforcers. Though not independently identified in the review by Wong et al., token economies are included some of the research articles included literature review and discussed in the review's reinforcement section. Token economies are frequently used within ABA programmes, leading to its inclusion in the manualized training programme.

In addition to these skills, several other strategies were included in the manuals. However, these additional skills were not included in the student skills assessment during the main study due to time restraints. Table 7.2 includes a full list of the course curriculum which includes all skills and topics taught.

6.3 Content Influenced by the Pyramid Approach to Education

While the ABA strategies identified have been shown to be effective, it is critical that they are applied in a systematic and meaningful way. To achieve this goal, the manual adopted the Pyramid Approach to Education (PAE) framework (Bondy, 2011). The PAE was developed by Dr. Andy Bondy and was designed to be applied to schools, clinics and home settings. The PAE provide a comprehensive framework for applying the ABA strategies in a functional manner. The PAE helps to organize effective teaching environments while utilizing the principles of ABA. The PAE model consists of eight elements: Functional activities, powerful reinforcement systems, functional communication and social skills, contextually inappropriate behaviours, generalization, lesson formats, prompting strategies, and error correction. Each of these elements either have their own course module or are embedded together in a module.

Table 6.2

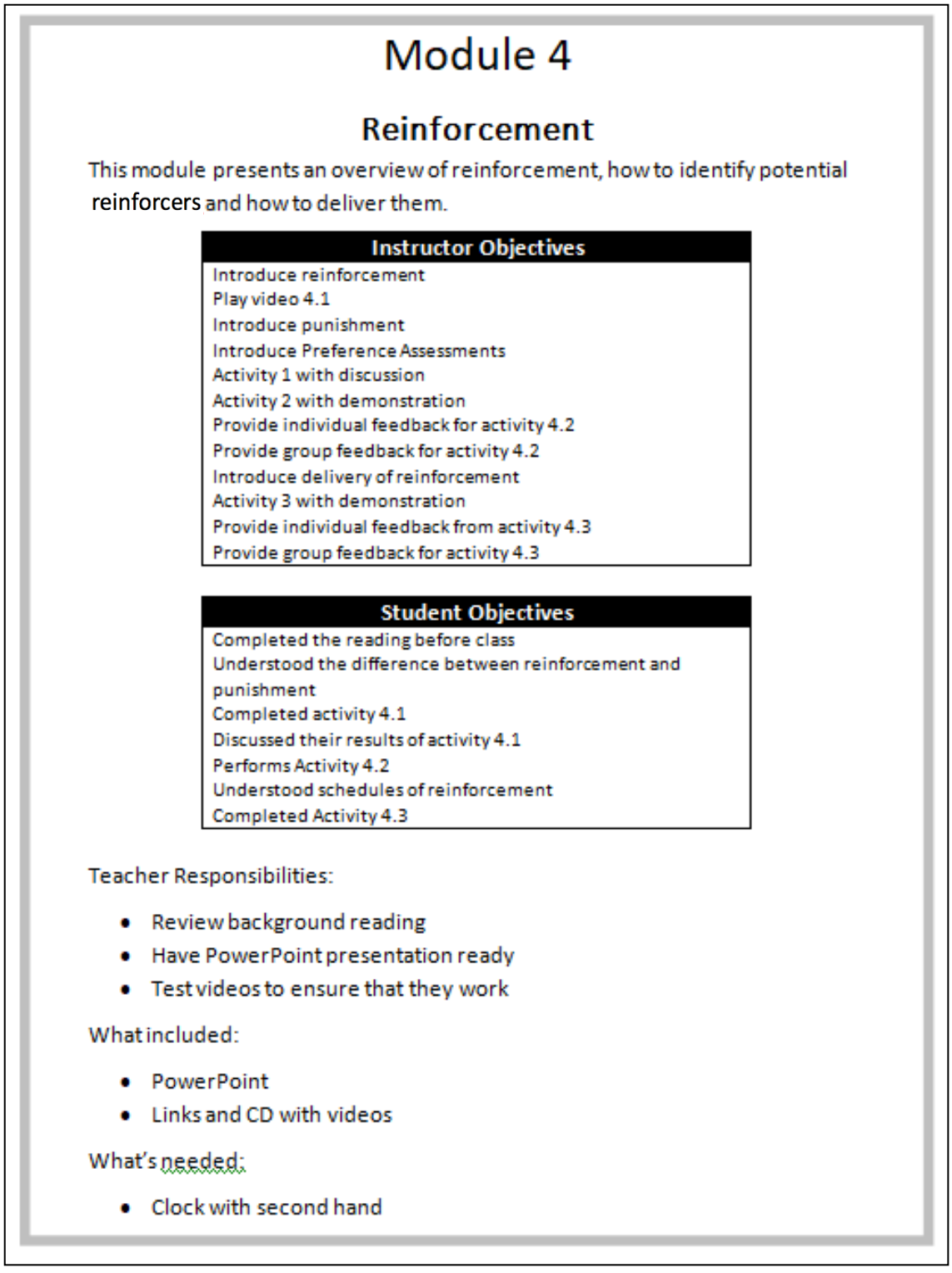
Pyramid Approach to Education Elements Embedded in the Course Modules

Module	PAE Element
1. Introduction	n/a
2. Autism	Functional Activities
3. Introduction to ABA	n/a
4. Reinforcement	Powerful Reinforcement Systems
5. Behaviour	Contextually Inappropriate Behaviour
6. Prompting and Shaping	Prompting Strategies
7. Teaching Strategies	Lesson Formats, Error Correction, Generalization
8. Communication Skills 1	Functional Communication and Social Skills
9. Communication Skills 2	Functional Communication and Social Skills
10. Token Economy	Powerful Reinforcement Systems
11. Ethics, myths, & misconceptions	n/a

6.4 Instructor Manual Features

The instructor manual is 117 pages long. It contains a table of contents, information about the training programme and use of the manuals, 11 sessions, implementation checklists, a 10 question multiple choice exam with an answer key for each module, and a 55 multiple choice question final exam with an answer sheet and answer key. The manuals also include component checklists and role play scenarios needed for the main study's pre- and post-training assessment. For the study, manuals were printed in black and white and comb-bound. The manuals came with a corresponding PowerPoint presentation with videos for each module.

Each module began with a summary page (see Figure 6.2). This summary page featured instructor and student objectives, teacher responsibilities, a list of materials and resources that are included and not included, and any additional materials that are needed to conduct the session.



Module 4

Reinforcement

This module presents an overview of reinforcement, how to identify potential reinforcers and how to deliver them.

Instructor Objectives
Introduce reinforcement
Play video 4.1
Introduce punishment
Introduce Preference Assessments
Activity 1 with discussion
Activity 2 with demonstration
Provide individual feedback for activity 4.2
Provide group feedback for activity 4.2
Introduce delivery of reinforcement
Activity 3 with demonstration
Provide individual feedback from activity 4.3
Provide group feedback for activity 4.3

Student Objectives
Completed the reading before class
Understood the difference between reinforcement and punishment
Completed activity 4.1
Discussed their results of activity 4.1
Performs Activity 4.2
Understood schedules of reinforcement
Completed Activity 4.3

Teacher Responsibilities:

- Review background reading
- Have PowerPoint presentation ready
- Test videos to ensure that they work

What included:

- PowerPoint
- Links and CD with videos

What's needed:

- Clock with second hand

Figure 6.2. Example summary page from the instructor manual.

The following page began with the instructor script. Each section had a heading that indicated what slide number corresponding to each section. A black line break indicated when the section was complete and that the instructor could proceed to the next slide. Within each section there were icons to specify when to play a video or complete an activity (see Figure 6.2). Bolded text represented comments to the instructor that are not meant to be read as part of the script. At the end of each module was an implementation checklist (see Figure 6.5). This checklist is completed at the end of the class to rate how well the instructor and student objectives were met. The instructors had the option of marking one of four responses; objective fully achieved, objective partially achieved, objective not achieved, or objective was not covered. The open-ended comment box at the bottom of the page provided additional feedback on the implementation of the module.

Instructor Script

1. Make any housekeeping announcements (e.g. any changes of classrooms, schedules or updated course policies)
2. Begin with slide show 1.

Slide 2

"Reinforcement is one of the most powerful systems at work in our world. Reinforcement shapes the way we behave and therefore greatly influences our future behaviour. Sometimes people equate reinforcement with just stickers and star charts, but it is so much more than that.

Reinforcement is a consequence that increases the chances of that behaviour happening again in the future. Let's look at an example. This woman wears a new red shirt. Her friend gives her a compliment. Now, she is more likely to wear that shirt again. In this example the consequence, which is the compliment, served as a reinforcer, as it increased the likelihood that the woman would repeat her behaviour."

Slide 3

"Let's watch a video example."

Play Video 4.1

"At first, everyone took the escalator. After the piano was attached to the steps, 66% more people took the steps. This was because the piano served as a reinforcer. This example shows you how a small adjustment to the environment using a reinforcer can have a significant impact on human behaviour."

Figure 6.3. Example of instructor script and video icon.

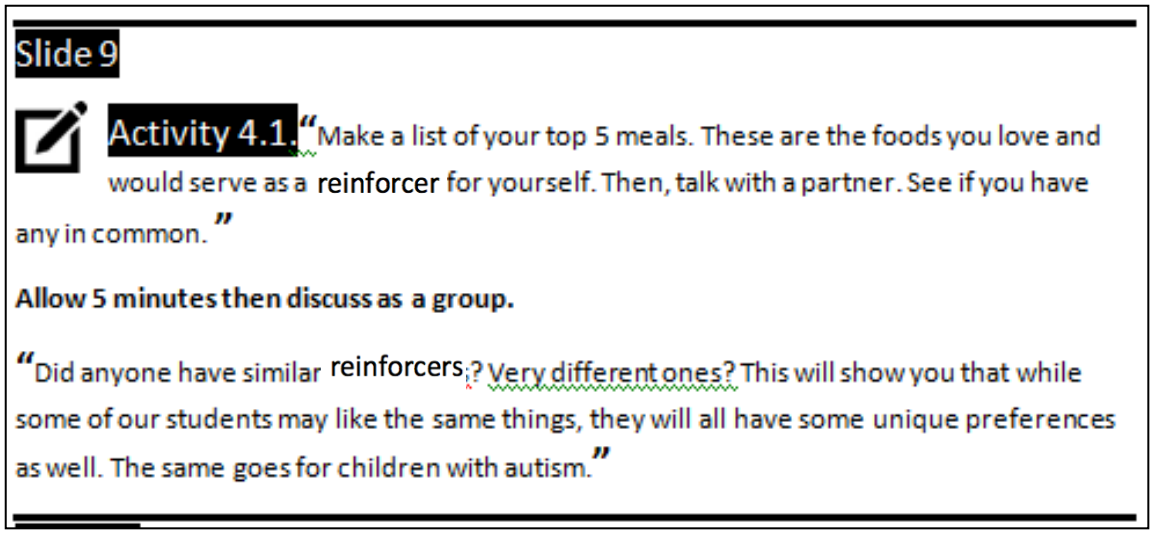
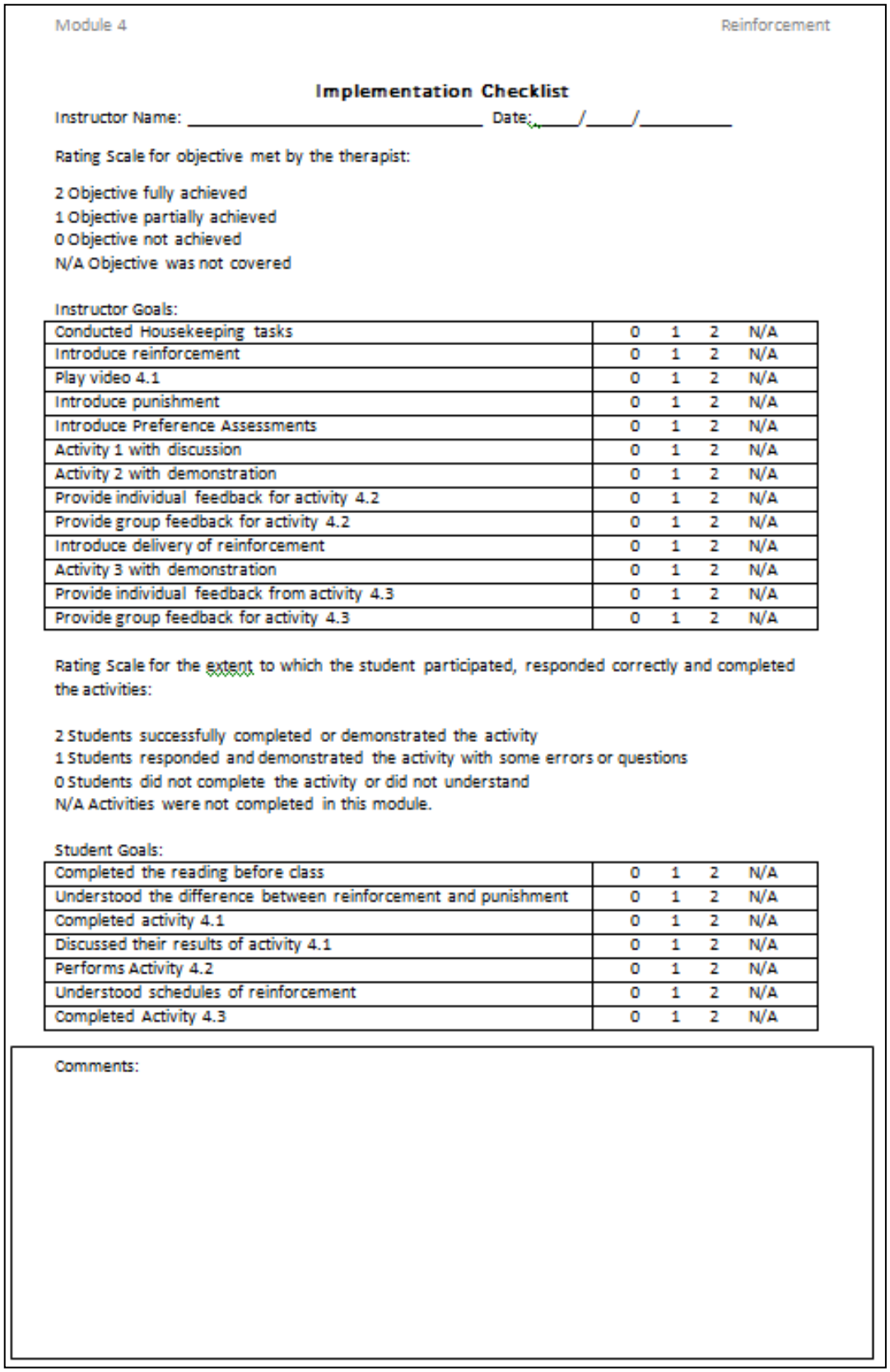


Figure 6.4. Example of activity icon and bold text in instructor manual.



Module 4 Reinforcement

Implementation Checklist

Instructor Name: _____ Date: ____/____/_____

Rating Scale for objective met by the therapist:

2 Objective fully achieved
1 Objective partially achieved
0 Objective not achieved
N/A Objective was not covered

Instructor Goals:

Conducted Housekeeping tasks	0	1	2	N/A
Introduce reinforcement	0	1	2	N/A
Play video 4.1	0	1	2	N/A
Introduce punishment	0	1	2	N/A
Introduce Preference Assessments	0	1	2	N/A
Activity 1 with discussion	0	1	2	N/A
Activity 2 with demonstration	0	1	2	N/A
Provide individual feedback for activity 4.2	0	1	2	N/A
Provide group feedback for activity 4.2	0	1	2	N/A
Introduce delivery of reinforcement	0	1	2	N/A
Activity 3 with demonstration	0	1	2	N/A
Provide individual feedback from activity 4.3	0	1	2	N/A
Provide group feedback for activity 4.3	0	1	2	N/A

Rating Scale for the extent to which the student participated, responded correctly and completed the activities:

2 Students successfully completed or demonstrated the activity
1 Students responded and demonstrated the activity with some errors or questions
0 Students did not complete the activity or did not understand
N/A Activities were not completed in this module.

Student Goals:

Completed the reading before class	0	1	2	N/A
Understood the difference between reinforcement and punishment	0	1	2	N/A
Completed activity 4.1	0	1	2	N/A
Discussed their results of activity 4.1	0	1	2	N/A
Performs Activity 4.2	0	1	2	N/A
Understood schedules of reinforcement	0	1	2	N/A
Completed Activity 4.3	0	1	2	N/A

Comments:

Figure 6.5. Example implementation checklist in instructor manual.

6.4.1 Supplemental instructional materials

Corresponding PowerPoint presentations were created for each session. Each presentation began with a title page including the main topic and the session number. The following slides included a combination of bullet points, pictures, tables, videos and text. Every slide displayed the page number to help the instructor follow along in their script.

The purpose of the PowerPoint presentations was to provide additional prompts to the instructors and to provide more information to students. Simple PowerPoints were originally created by the primary researcher and were subsequently translated and adapted for use in Kazakhstan. The mothers were permitted to adjust the PowerPoints to suit their presentation style. Video examples were created and embedded in the PowerPoints. The videos were in Russian and made in Kazakhstan to be culturally relevant. For example, materials the students would be familiar with such as food, toys, and clothing were used. The scenes in the videos were all recorded in homes and clinics in Kazakhstan and all the participants spoke Russian. The videos were shot using an iPhone camera and featured the mothers of children and their autistic or typically developing children.

6.4.2 Materials for pre- and post-training assessments.

The main study involved pre- and post-training skills assessments. All material needed to complete these skills assessments were included in the appendix of the instructor manual. This included a role play scenario for each skill, to be read aloud by the instructor. The role play scenarios were created by EM, a BCBA and doctoral candidate, and verified by a second researcher, JA, who is a clinical psychologist. The role play scenarios were intended to be clear, concise and as realistic as possible.

A component checklist was created for each skill. The checklist consisted of the essential steps of each ABA strategy and was included in the appendix of the instructor manual. The component checklists were initially based on the implementation checklists

created by the NPDC and used as part of the Autism Focused Intervention Resources and Modules (AFIRM). These checklists were adapted to check the degree and quality of fidelity to the training programme developed for the main study The checklists feature a space for the observer to mark if each step was done correctly or incorrectly, and finish with place to indicate how many steps were performed correctly out of the total number of steps.

The instructor manual also included a 55-question exam, with questions directly related to information in each session. All questions were either multiple choice or true/false questions (38 multiple choice, 17 true/false). For each multiple-choice question, 4 answers were provided with only 1 correct answer. The questions were divided evenly to cover content from each of the 10 sessions. Two versions of the exam were created, one for pre-training and another for post-training. The pre-training versions included the option to answer "I don't know." The post-training version did not have this option; forcing the students to make a selection. A separate answer sheet was included for the students to record their answers.

6.5 Student Manual Features

The student manual was 111 pages long. It included a table of contents, information about the course, ten sessions, an appendix consisting of glossary of terms, sample data collection sheets, materials for in-class activities (flash cards), and component checklists. For the study, manuals were printed in black and white and spiral bound.

The structure of each session was consistent throughout the manual for easier use. Each session began with the title in bold, followed up a list of key vocabulary terms and their definitions (see Figure 7.5). The purpose of the key terms was to aid the students in learning the new ABA terminology.

Following the key terms was the pre-class reading. The length of the pre-class readings ranged from two to five and a half pages long (M=3.8). Each pre-class reading

began with a section explaining the behavioural concept and linking it to a typical everyday life example (see Figure 6.6). Following this section was a clear description of how those concepts translate to teaching strategies and how those strategies can be used with children with autism (see figure 6.7). The pre-class readings also often included real-life examples, tips on strategy implementation, and visual aids.

At the end of the pre-class reading was a section titled 'Dealing with Difficulties.' This section provided tips and practical advice regarding what to do when problems arise during the lessons with children. The section ended with a thick grey line at the bottom, indicating the end of the pre-class reading (see Figure 6.8). After the readings, the in-class activities were explained. These activities included individual, pair and group discussions, as well as practice sessions of the ABA teaching strategies. Each activity was labelled and included instructions for the completion of the activity (see Figure 6.9).

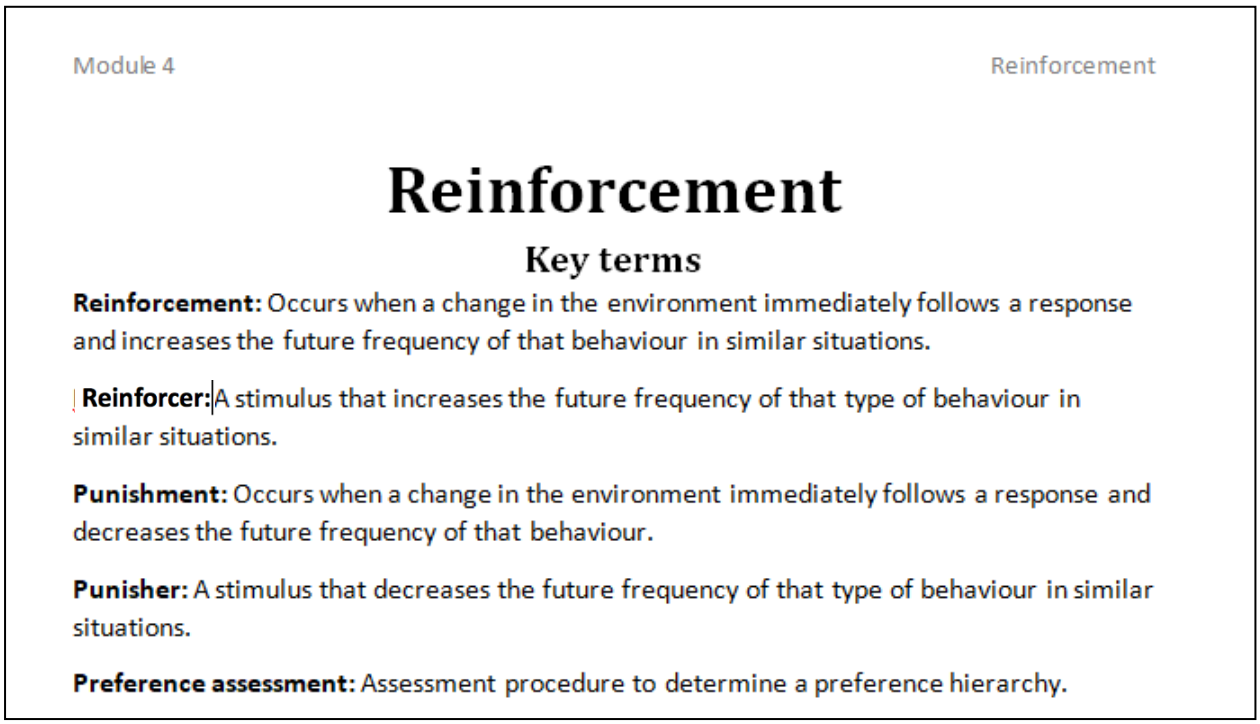


Figure 6.6. Module title and key terms in student manual.

Reinforcement in our everyday lives

You may have heard of positive reinforcement before in the context of parenting. However, what you might not realize is that there are systems of reinforcement that influence our behaviours all day long! Before we get into how you can use reinforcement to help better teach your students, let's look more closely into what reinforcement is and how it affects our daily lives.

Figure 6.7. Examples of pre-class reading in the student manual.

When to give reinforcement

Now that you have identified potential reinforcers for your student, you need to make a plan for how often to give those reinforcers. When teaching a new skill or behaviour, you will need to provide more reinforcement. As the student masters the skills, you can begin to reduce the amount of reinforcement you give them. This should be done systematically, so you don't reduce levels of reinforcement at the wrong time. The term for how often to provide reinforcement is called *schedules of reinforcement* and there are two broad categories: continuous and intermittent.

Figure 6.8. Examples of applying ABA principles while teaching children with autism in student manual.

Dealing with Difficulties

- If you have issues using reinforcement, it is possible that the item you are using as a reinforcer has lost its value. Our students can become bored of items and therefore they are no longer reinforcing. If this is the case, try switching to a different item
- Be sure to provide reinforcement within ½ second for new skills
- Provide reinforcement for your students all day long, not just at the end of the day
- Pair tangible reinforcers (toys, games) with social reinforcement and praise
- Activities or social interactions can be used as reinforcers for students (tickles, swinging, painting, listening to music)

Figure 6.9. Examples of concluding statements in the student manual.

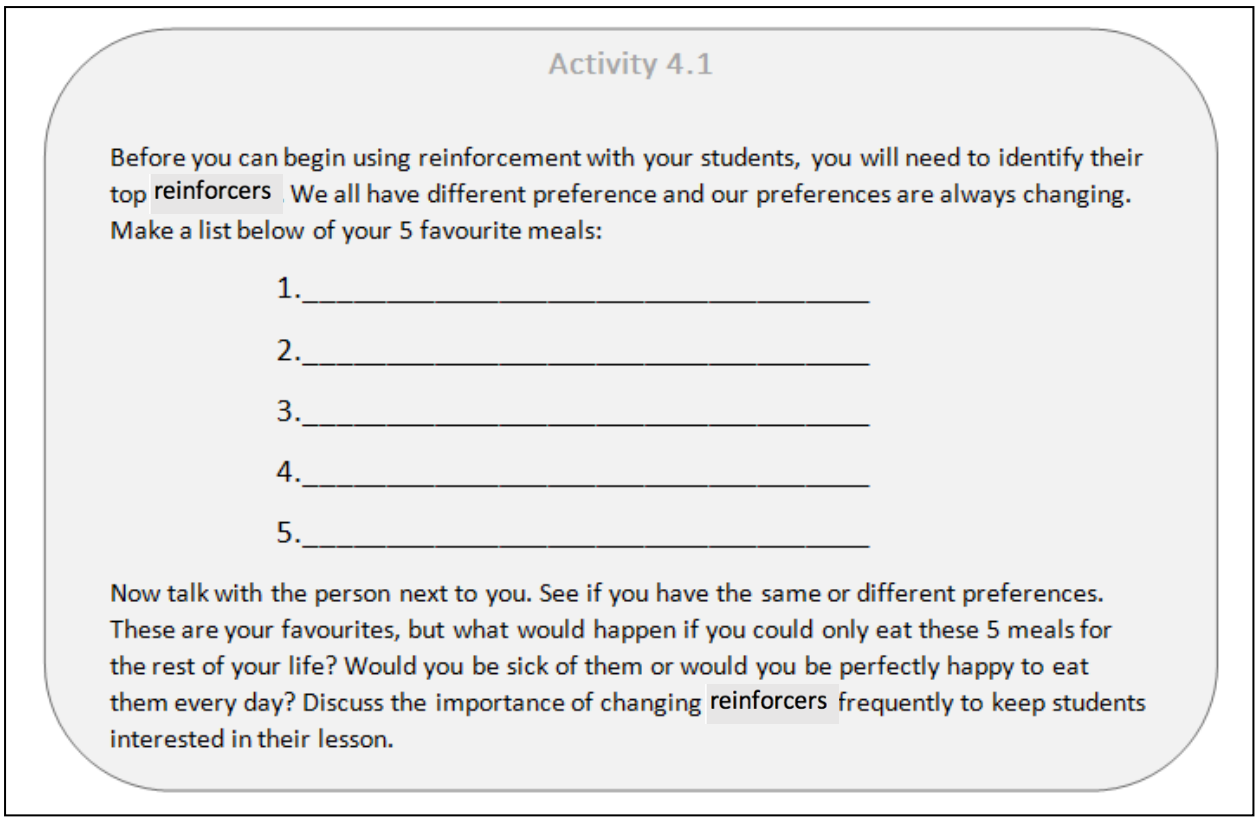


Figure 6.10. Examples of an in-class activity in the student manual.

6.5.1 Supplemental student materials

The student manual appendix included several additional resources. Appendix A included a glossary of all key terms from the modules. Appendix B included sample data collection sheets that could be photocopied and used at a later date in a work setting. All materials needed to complete in-class activities (flashcards, tokens, etc.) were placed in Appendix C. Finally, copies of the component checklists were provided in Appendix D.

6.6 Structure Based on Behavioural Skills Training

The delivery of this course was based on behavioural skills training (BST), an evidence-based approach to staff training. BTS includes four components: Instruction, model, rehearsal, and feedback (see section 2.5 for a detailed description of BST). The manuals were designed to follow this approach for each ABA strategy. Before each session the students were required to complete the pre-class reading assignment. This reading assignment is part of the first step of BST, the *instruction*. At the beginning of each session the instructor provided a brief, scripted lecture. This lecture served as the second half of the *instruction*. The instructor either played a video example or demonstrated the skill as the *model.* Following the model, the students *rehearsed*, or practiced, with one another. After the *rehearsal*, the instructor provided individual and group *feedback*.

Table 6.3

Summary of Behavioural Skills Training Components

Step	Component
Instruction	Student pre-class reading Instructor presents scripted lecture with PowerPoint
Model	Video Model and/or Instructor demonstration
Rehearsal	Students practice with each other
Feedback	Individual feedback from instructor during rehearsal Group feedback following rehearsal

6.7 Translation and Cultural Adaptation

The translation of the manual from English to Russian was completed by university-based local Kazakh translators. An official list of Russian language ABA terminology was obtained from the BACB and was provided to the translators to improve consistency of terminology throughout the course and to alleviate the stress of translating terms that are unique to ABA. A primary and secondary translator was assigned to each module. The primary translator was responsible for the initial English-Russian translation, while the secondary translator reviewed and verified the module translation. Any queries were discussed between the translators and input from the researcher was available to clarify the meaning of any section of the manual. The manuals were also reviewed by the local clinical director and her husband, both certified translators and parents of a child with autism who have received previous training in ABA. This review served as a final screening for translation errors and the appropriateness of the manual for the cultural context of Kazakhstan. Alterations and adjustments to the manual were made where appropriate based on their feedback.

7. Main Study

Research Aim 4: Assess and evaluate the feasibility, acceptability, and efficacy of the training programme.

Abstract

Treatments based on the principles of applied behavior analysis (ABA) are largely unavailable to individuals living outside of the United States. This is due, in part, to a lack of trained professionals and training programmes available globally. The aim of this study was to develop a two-week manualized behavioral skills training program to teach ABA procedures to university students in Eastern Kazakhstan. Using a pyramidal training approach, seven mothers of children with autism were trained to deliver an ABA behavioral skills training programme. Students' performance of eleven ABA procedures and knowledge of autism and basic ABA principles were assessed pre- and post- training. Mothers delivered the training with a high degree of fidelity (M = 93.00, SD =12.31). Student scores on all ABA procedures improved by an average of 81 percentage points post-training. Both students and mothers reported high levels of satisfaction with the programme. The present study provides a framework for delivering an effective behavioral skills training package using a pyramidal training model with parents as trainers, extending the reach of evidence-based interventions to new countries.

For individuals with autism, effective interventions can lead to improved outcomes (Smith, Hayward, Gale, Eikeseth, & Klintwall, 2019). A 10 year follow-up study found that children who received two years of early intensive behavioural interventions had improved cognitive and adaptive skills, and those skills were maintained over the 10 year period (Smith, Hayward, Gale, Eikeseth, & Klintwall, 2019). Despite the success of these treatments, behavioural interventions remain out of reach for many families living in countries with few qualified professionals, such as Kazakhstan. Kazakhstan is the ninth largest country in the world in terms of land, but is one of the least densely populated countries. Access to education and interventions for individuals with autism is limited (An & Chan, 2018). This is consistent with previous research that suggests that evidence-based practices (EBP) are less available to children with autism living in rural areas versus non-rural areas.

An EBP approach includes practitioners basing clinical decisions on the current scientific evidence, their clinical experiences, and their client's values (Zane, Weiss, Davis, & Melton, 2016). A number of professional bodies, including the American Psychological Association, Council for Exceptional Children, and the National Autism Center, recommend the use of evidence-based practice (EBP) when treating children and adults with autism. Research has shown that EBPs for the treatment of autism can be delivered by professionals, teachers, and parents (Vaughn & Dammann, 2001). Wong et al. (2013) conducted a systematic review of interventions commonly used in treatment programmes for children and adolescents with autism. The review analysed 456 articles and found twenty-seven interventions that met the standards for EBPs. Of the twenty-seven interventions, 17 were based on the principles of applied behavior analysis (ABA).

Services based on the principles of ABA are often delivered by Board Certified Behavior Analysts ® (BCBA), who obtain their certification after the successful completion of graduate studies, supervised fieldwork, and a written exam. However, as of January 2020, only 3,184 of the 37,859 BCBAs reside outside of the USA (BACB, 2020). Additionally, there are only 110 approved BCBA graduate programs outside of the USA, as compared to the 399 approved programs in the USA (ABAI, 2020). For those not residing in the USA or one of the 44 countries with a verified course sequence (VCS), the distance programs in the USA are often too expensive, leaving training inaccessible. For families living in countries without BCBAs, it is often too costly to bring their child to another country for treatment, leaving therapy based on the principles of ABA out of reach for many children with autism and their families. With the lack of professionals and approved training programs, careful consideration should be given to how to effectively train staff in locations outside of the USA, in particular those residing in rural areas of developing countries.

There are several approaches to staff training which could be considered. Traditional staff training is delivered in a didactic form, with the instructor providing information to the trainee. Didactic training can be effective for teaching knowledge, but less effective for teaching the competencies and skills needed for the successful delivery of behavioural intervention (Alavosius & Sulzer-Azaroff, 1990; Lerman, Vorndan, Addison, & Kuhn, 2004; Petscher & Bailey, 2006). Alternatively, behavioural skills training (BST) is a well-researched training package that can be used to teach professionals how to implement ABA procedures (Parsons, Rollyson, & Reid, 2012). BST has been shown to be an effective way to teach a variety of skills, including assessment and functional analysis, the Picture Exchange Communication System (PECS) and behaviour management techniques (Homlitas, Rosales, & Candel, 2014; Iwata et al., 2000; Miles & Wilder, 2009; Sawyer, Crosland, Miltenberger, & Rone, 2015). BST involves four components: *(1) Instruction*: either written or verbal**,** to

provide a rationale for the target skills and explain how to successfully implement the skills. *2) Model***:** a live demonstration of the skill by the instructor, or a video model. *3) Rehearsal:* the student practices the skill in a role-play or a real-life setting. *4) Feedback:* the instructor gives feedback to the individual or group based upon their performance during the rehearsal. Positive feedback is given for skills performed accurately, and corrective feedback is given if mistakes are made. In the event of a mistake, the student will rehearse or practice the skill and receive feedback until the skill is performed in a manner consistent with the instructions.

Most BST research has focused on teaching a small number of EBP to a small group of participants, using a multiple baseline across participants design. One of the largest BST studies was conducted at a large American university and used BST to teach seven undergraduate pre-service special education teachers to implement seven different EBPs using role play scenarios (Sawyer et al., 2017). Before and after the training the students were asked to perform an evidence-based strategy in a role play scenario. Their performance was scored using a competency checklist of the critical steps for implementing the EBP. The number of correctly performed steps was divided by the total number of steps to yield a percentage score. This study found that on average, skill performance improved by 75 percentage points for each skill. The results suggest that university courses could be enhanced and students could benefit from the incorporation of BST into traditional lectures. However, the study delivered the training in very small groups of three or four students. It has yet to be determined if BST can be delivered to a larger group of students attending a university course.

While there is some evidence for the success of delivering BST in the university setting, there are barriers towards achieving the same quality of training in developing countries. For example, in most studies the training is delivered by a university-based researcher with postgraduate training (and often a doctoral degree) and the training is very

time consuming for the professional delivering the training (Karston, Axe, & Mann, 2015; Parsons, Rollyson, & Reid, 2013). This is problematic for countries where there are no BCBAs, nor doctoral level researchers with experience in ABA. It is important to establish if BST can be carried out successfully by individuals without a doctoral degree or advanced training in ABA. Determining what level of training the trainer requires to effectively deliver BSTs will help to increase the reach and accessibility of evidence-based intervention for children with autism.

One approach to address this issue is to use a pyramidal training approach, or train-the-trainer model (Pence, Peter, & Tetreault, 2012). In this approach, a highly skilled professional trains a small group of individuals, who then train other individuals. Pyramidal training lessens the demand for highly qualified professionals and builds the skills of the less qualified professionals (Demchak & Browder, 1990). Parsons, Rollyson, and Reid (2013) used a pyramidal training approach to teach nine teachers how to train their own staff members to implement new EBPs. The teachers selected EBPs they were currently using and could implement with a high degree of fidelity. Teachers then used BST to train new staff members to implement the selected EBPs. The training provided followed the BST protocol: first teachers were provided with instructions for delivering the training, then the training was modelled, then the teachers rehearsed and received feedback on their delivery. Following training, the researchers observed the teachers in their settings delivering BST to staff. Using a competency checklist, the researchers determined how many of steps of the training that each teacher performed accurately. Seven out of nine teachers implemented BST with 100% accuracy, while two teachers implemented BST with 88% accuracy. This study provides evidence for the use of BST to train teachers to utilize this procedure to train their own staff to implement EBPs. However, it is unclear if this procedure would be effective for training teachers without existing mastery of the EBP.

The pyramidal approach is likely to be useful for increasing access to treatment in countries with no or few qualified BCBA professionals, particularly those living in rural locations or settings that lack local highly skilled professionals, such as Eastern Kazakhstan. Employing international consultants is very costly and is unaffordable to many Kazakhs. The few available specialists are based in the major cities of Nur-Sultan and Almaty. With Kazakhstan being the ninth largest country in the world and one of the least densely populated countries, those living outside the major cities have few options. A pyramidal training approach could therefore help to decrease the time and costs associated with employing international specialists and traveling to bigger cities. It could also provide a sustainable method for training professionals around the country to not only use EBPs, but to effectively teach others to use EPBs. In Kazakhstan, and as with many countries, parent groups have taken the lead with autism awareness and reform efforts (Markova & Sultanalieva, 2013; Rouse, Yakavets, & Kulkhmetova, 2014). The enthusiasm of these parent groups makes them a promising candidate to deliver a training programme to university students.

The aim of the present study is to evaluate a class-wide BST programme, teaching pre-service teachers and psychologists enrolled in undergraduate and postgraduate programmes at a university in rural Kazakhstan to implement ABA strategies. For this study, selected EBPs (*skills* henceforth) will be taught to mothers of children with autism. Mothers were trained to deliver the BST program to undergraduate and graduate students using a pyramidal training framework. The training was provided by the first author and followed a BST model. The feasibility, acceptability, and effectiveness of the program in teaching both knowledge and skills were assessed.

7.1 Phase 1: Parent Training

7.1.1 Methods

Participants

Six mothers of children with autism and one mother of a child with pervasive developmental disorder not otherwise specified (PDD-NOS) participated as Parent Instructors in this study. Parent Instructors' ages ranged from age 31- 48 (M = 35.7, SD = 6.47) and all were the child's biological mother. Four of the Parent Instructors reported their ethnicity as Kazakh and three as Russian. All Parent Instructors were married; two reported being in a high-income household and five reported middle-income households. Five Parent Instructors had completed undergraduate degrees, one Parent Instructor reported attending some college, and one Parent Instructor had a postgraduate degree.

Their children were four boys and three girls aged from 5 - 10 years (M = 6.85, SD = 1.72). Child characteristics are shown in Table 7.1. All children attended a local centre that provides educational services for children with developmental disabilities, with children receiving and between 10 and 30 hours a week of services at the center. The Parent Instructors were recruited by the director of the center to participate in this study and were selected based on their eagerness and enthusiasm to learn ABA. All Parent Instructors had no prior training in ABA, except one who had previously attended two-week introductory ABA course.

Setting

All Parent Instructor assessments and training sessions were held at the center for children with disabilities. The training sessions took place in one of two large rooms with tables and chairs, while the individual skills assessments were conducted in a separate room used for one-on-one therapy sessions. All PowerPoint presentations displaying content for each training session were presented on a laptop computer. During the assessments and training, one or two translators were present.

Table 7.1

Child Characteristics of Parent Instructor Participants in the Study.

Child Age	Child Ethnicity	Weekly hours	Diagnosis	Age at Diagnosis	Medications	Add. Illness
8	Kazakh	30	autism	2	Glycine Cogitum Gammalon memantinum	None
6	Russian	12	autism	3	None	None
10	Russian	30	autism Apraxia	2	None	None
8	Mixed	23	autism	4	Omega 3, 6, 9 B6, 12	None
5	Mixed	16	autism ADHD	4	None	None
6	Kazakh	17.5	Autism ADHD PDD-NOS	4	Vitamins	Myotonic-dystrophy
5	Russian	10.5	ADHD Apraxia OCD Anxiety	3	Sonapax Pantocalcin	None

Note. *OCD*, obsessive-compulsive disorder; *ADHD*, attention-deficit hyperactivity disorder; *PDD-NOS*, pervasive developmental disorder not otherwise specified.

Materials

Ten skills were selected based on their inclusion on the BACB's Registered Behavior Technician task and identification by Wong et al. (2013) as the skills with the strongest evidence base and those considered necessary for entry-level therapists. The skills featured in the training program are listed in Table 7.2. A component checklist, including the essential steps for implementing each skill, was created by the primary researcher (a BCBA enrolled in a PhD programme) and checked by the secondary researcher (JA; is a clinical psychologist). The component checklists were used to score the participants during the *skills assessment sessions, rehearsal probes, and in-training checks.* For each skill, a '+' was recorded for a completing a correct step on the checklist and a '-' was recorded if the step was not performed or if was performed incorrectly. The number of steps performed correctly was divided by the total number of steps to yield a percent correct of the skill. This percentage served as the *skills assessment* score for each individual skill.

Two separate manuals were created by the author for use in this study; one for the Parent Instructors and one for the university students (see Chapter 6 for more details). When possible, non-technical language was used, as research has suggested that jargon-free training materials lead to better performance and increased accessibility (Graff & Karsten, 2012). The instructor manual included a set of instructions for manual use, background information on ABA and autism, the rationale for the training program, and 11 individual one –hour session chapters. PowerPoint presentations were provided for each session. The Parent Instructors were told that scripts could be read word-for-word or paraphrased, provided that all of the instructor objectives were met. Each chapter began with an information page listing both the instructor and student objectives, materials provided for the session (flash cards, token boards, etc.) and materials needed (e.g., toys, pens). The information page was followed by a script which included verbatim instructions, when to move on to the next slide, play videos,

and perform the individual and group activities. An implementation checklist was included at the end of each chapter with instructor and student objectives (e.g., X skill was performed, theoretical principles of behavioral intervention were explained). The checklist also included a section for instructors to provide feedback on individual components of the course for future revisions.

The student manuals included general course information (e.g., aims, classroom expectations), an outline of the training program, and 11 session chapters covering psychoeducation about autism and the selected skills. Each chapter included a brief reading assignment as an introduction to the topic to be completed before class. The manuals included all materials (flash cards, tokens, etc.) needed to complete the in-class activities. The appendix includes a glossary of terms and sample data collection forms.

Table 7.2

Training Course Outline

Session	Content	Skills gained
1. Introduction	Course structure and evaluation Programme aims Pre-course questionnaires	
2. Autism	Introduction to autism	
3. Introduction to ABA	History of behaviourism, theoretical principles of ABA and how to collect data	Data collection
4. Reinforcement	Principles of reinforcement and punishment, identifying reinforcers and how to deliver reinforcers	Preference Assessments Schedules of reinforcement
5. Functions of Behaviour	Explaining human behaviour, operationally defining behaviour, a functional approach to analysing behaviour, and methods for changing behaviour	Functional Analysis
6. Prompting and Shaping	Different types of prompts and prompting strategies, using shaping to teach new skills	Prompting Shaping
7. Teaching Strategies	How to design lessons to teach new skills and how to deal with errors	Discrete Trial Training Task Analysis Chaining Error correction
8. Communication Skills 1	Defining functional communication and a behavioural approach to language development	Mand training Teaching 'Yes' Teaching 'No'
9. Communication Skills 2	Teaching additional communication skills	Requesting Help Waiting Accepting 'no'
10. Token Economy	Introduce token economies and how to use them with individual students and groups	Token board
11. Ethics, misconceptions and career options	Discuss ethical practice (including misuse of treatment strategies), common misconceptions about ABA, and career options	

The translation of the manual from English to Russian was completed by Kazakh translators based at a local university. An official list of Russian language ABA terminology was obtained from the BACB and provided to the translators to ensure consistency of terminology throughout the course. During Phase 1 of training, Parent Instructors were encouraged to provide feedback on the manuals in order to fix any translation errors that were overlooked. Changes to ensure clarity of wording and to ensure the appropriateness of the manual for the cultural context of Kazakhstan were made based on feedback from the translators, with further changes made on the basis of the input of the Parent Instructors.

The Family Empowerment Scale (FES) was used to assess Parent Instructors' report of parental empowerment pre- and post- intervention (Koren, DeChillo, & Friesen, 1992). The FES is a 34-item questionnaire with a 5-point rating scale ranging from 1 'not true at all' to 5 'very true.' The FES consists of three subscales: Family (the parent's ability to manage day-to-day situations), Service System (parent's ability to work with professionals and access services their child needs), and Community/Political (parent's ability to advocate in the community to improve services for all children, not just their own). The FES has shown good internal reliability, with subscale scores of $\alpha = .88$, $\alpha = .87$, and $\alpha = .88$ (Koren, DeChilo, & Friesen, 1992). The FES has previously been used with parents of children with developmental disabilities (Thompson et al., 1997).

Procedure

Ethical approval for this study was obtained from the university ethics board. Written informed consent forms was obtained from Parent Instructors and students before the study commenced. A flowchart detailing the process for Phase 1 is displayed in Figure 7.1. The Parent Instructors completed demographic questionnaires and the FES. The Parent Instructors then complete the pre-training skills assessment. After completing the assessment and questionnaires, Parent Instructors participated in the parent training course. Daily three-hour

training sessions took place at the centre for seven consecutive days (21 hours training in total). The structure of the training course was based on the BST-based pyramidal teaching approach implemented by Parsons et al. (2013). The first four days of training consisted of the researcher providing the full, 11 session training program to Parent Instructors in the same manner as the training was intended to be delivered to the university students. This served as the *instruction* and *model*. The final three days included the *rehears*al and *feedback* components of BST. The Parent Instructors practiced delivering the course and prepared to present the sessions to the university students in Phase 2.

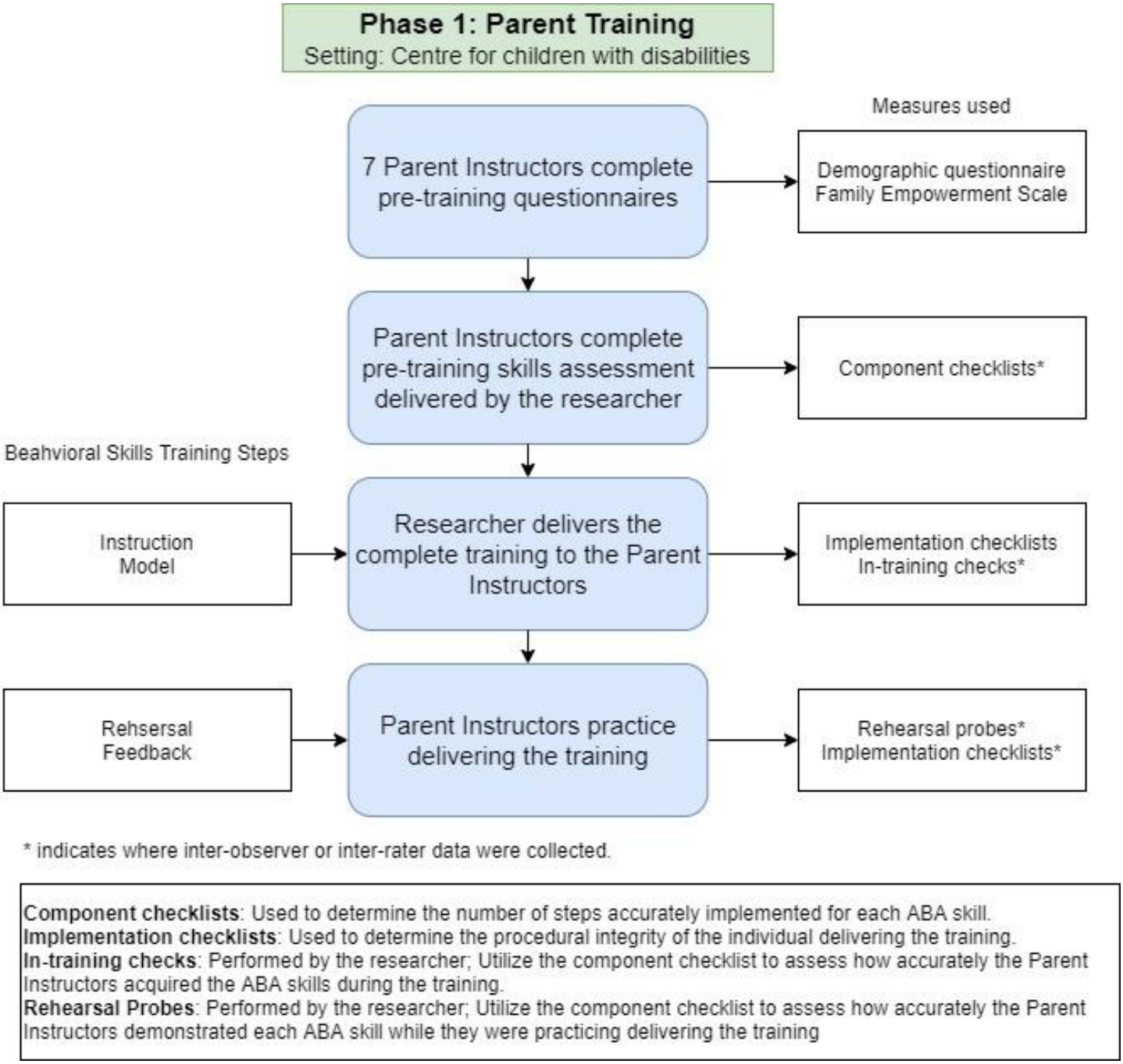


Figure 7.1. Flowchart of Phase 1 procedures.

Pre-training skills assessment

The skills assessments were performed to assess the Parent Instructors' baseline performance of the skills. The researcher provided the Parent Instructors with a copy of the component checklists and all materials necessary to complete the skills successfully (toys, flash cards, etc.). The researcher read aloud a scenario about an autistic child and instructed the Parent Instructors to perform the skill to the best of their ability. The researcher served as the 'child' during the assessment and performed the actions necessary to allow the Parent Instructors to fully implement each skill. If a Parent Instructor was unfamiliar with a skill, she was instructed to say 'pass'. The number of steps performed correctly were divided by the total number of steps and multiplied by 100 to yield a percentage score.

Parent training

During the initial training, the mothers completed the pre-class readings as the first part of the *instruction*. The researcher then followed the script and PowerPoint for a brief presentation as the second part of the instruction. The researcher then *modeled* and/or played a video model for each ABA skill. The Parent Instructors *rehearsed* the skills with one another. The researcher then performed '*in-training checks'* using the component checklist to ensure that each Parent Instructor implemented each skill accurately. The researcher walked around the room and observed the Parent Instructors one-by-one. All Parent Instructors were required to meet the mastery criteria of 100% accurate implementation of each skill during these checks. If the Parent Instructor scored 100%, the researcher would provide *positive feedback*. If the Parent Instructor did not score 100%, the researcher would provide *corrective feedback* and repeat model the skill. The Parent Instructor would then make a second attempt to implement the skill. This process was repeated until the skill was performed with 100% accuracy. Once the session was finished, the researcher would begin the next session and this process was repeated for all subsequent sessions.

After the Parent Instructors had received the full training, they *rehearsed* the delivery of the training sessions by presenting at least one session to the group. Each session included at least one ABA skill. During the presentations, a '*rehearsal probe'* was performed by the researcher to assess whether or not the skills in the session were demonstrated correctly. The researcher used the component checklist while observing the presentation to score each skill. If correct, the Parent Instructors received positive feedback from the researcher and the other Parent Instructors. If the skill was not demonstrated with 100% accuracy, the researcher would provide corrective feedback and model the skill. The Parent Instructors would then rehearse the skill until it was performed accurately in front of the group. The researcher and Parent Instructors completed implementation checklists for these presentations to monitor procedural integrity. Answers were compared and discussed to ensure the Parent Instructors could correctly complete the implementation checklists.

The training also included a 30-minute supplemental session on public speaking delivered by the researcher. The Parent Instructors also received an additional 3-hour training session in preparation for delivering the skills assessments to the university students. Between one and three translators were present during all training sessions to aid communication between the researcher and the Parent Instructors. Translators also assisted in adjusting the manuals to enhance clarity and the cultural relevance and appropriateness of content.

Procedural integrity and rater reliability

The researcher completed the implementation checklists to monitor fidelity for the initial delivery of the training to the Parent Instructors. The researcher implemented the training with 100% accuracy. Procedural integrity was also assessed during the rehearsal to ensure that the Parent Instructors were adhering to the training programme manual. An implementation checklist was used for each session to determine if the Parent Instructors met

the set objectives for both instructors and students. The implementation checklist was completed by the researchers and the non-presenting Parent Instructors after observing each presentation. All sessions were presented with 100% fidelity, except for Session 10, which scored 89%. Skills assessment scores collected by the researcher and a trained assistant for 43% of pre-training skills assessments (32 individual 'skills' scores). A two-way random-effects test was run to assess interclass coefficients. A high degree of reliability was found between the two raters. The average measure ICC was .987 with a 95% confidence interval from .975 to .994 ($F(32, 32)= 79.754$, $p<.001$).

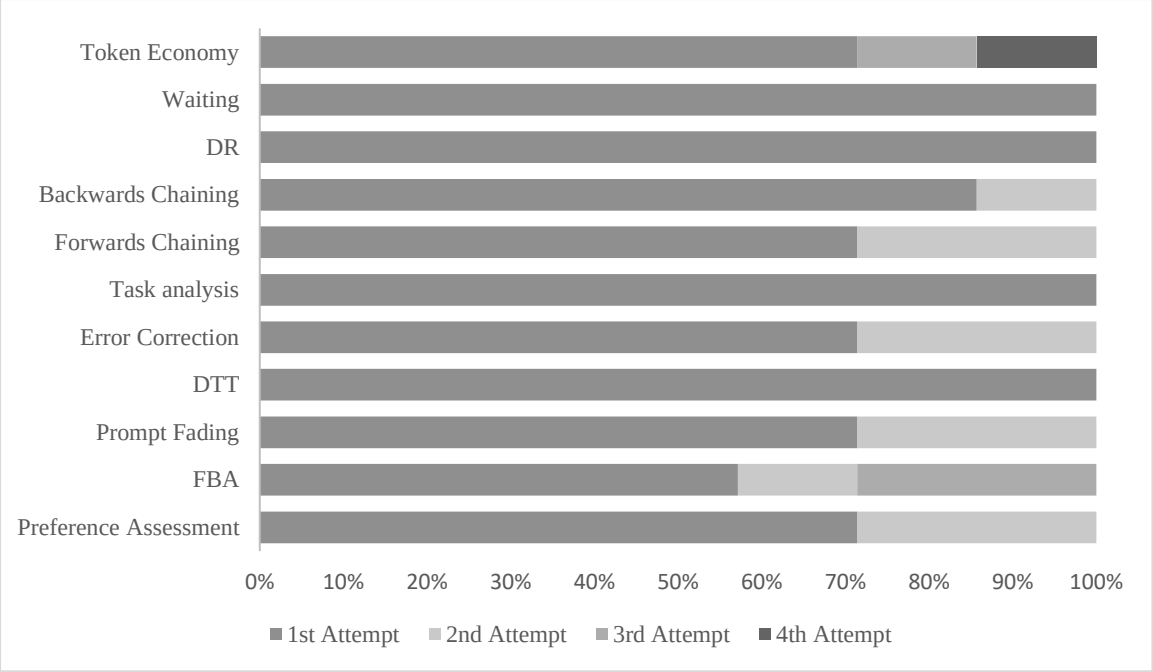
7.1.2 Results

Parent Instructor pre-training skills assessments

Parent Instructor pre-test scores were low, but variable. Task analysis rated the lowest (M = 7.17, SD = 17.49), followed by forwards and backwards chaining (M = 10.71, SD = 26.24), preference assessment (M =15.44, SD = 18.81), functional behaviour assessment (M = 16.3, SD = 29.10), waiting (M = 26.42, SD = 25.72), token economy (M = 26.57, SD = 25.73) prompt fading (M = 33.14, SD = 16.82), differential reinforcement (M = 34.71, SD = 19.22); with the highest scores obtained for error correction (M = 46.85, SD = 39.53) and discrete trial training (M=46.85, SD = 41.59).

In-training checks

All Parent Instructors met the mastery criteria during the in-training checks (100% accurate implementation of each skill based on the component checklist). Most Parent Instructors met the mastery criteria of each skill on their first attempt, but some skills required up to four attempts (see Figure 7.2).



Note. DR, differential reinforcement*; DTT,* discrete trial teaching*; FBA,* functional behaviour assessment.

Figure 7.2. Number of Parent Instructor attempts to master each ABA Skill during the in-training skill checks. For example, all mothers implemented Task Analysis correctly on their first attempt.

Rehearsal Probes

Each ABA skill was assessed using the competency assessment during the rehearsal phase, where Parent Instructors practiced delivering the sessions. Functional behaviour assessment (FBA), prompt fading, discrete trial teaching (DTT), task analysis (TA), forwards chaining, backwards chaining, differential reinforcement and waiting were all presented with 100% accuracy on the first attempt. Preference assessment and error correction were presented correctly on the second attempt, after the researcher provided corrective feedback and modelled the skill again. Token economy was implemented correctly on the fourth attempt, following three rounds of modelling and feedback.

7.2 Phase 2: University Student Training

7.2.1 Methods

Participants

The head of the Psychology Department at the local university invited 30 university students to participate in the study. Participation was not mandatory for enrolment in the training course. Of the 30 university students invited, 21 chose to take part in both the training course and the study (two graduate students and seven undergraduate students opted not to participate). The university student sample comprised 7 undergraduate students and 14 graduate students (four of which were concurrently working as teachers). Undergraduate students (six female, one male) majored in Psychology (*n*=3), Defectology[7] (*n*=3), or Education (*n*=1). University student ages ranged from 17-22 years (*M* = 20.42, *SD* =2.14). Students were in their first (*n*=2), third (*n*=1) and fourth (*n*=4) year of study. Graduate students (13 female, one male) had undergraduate degrees in Psychology (*n*=8), Defectology

[7] *Defectology* was created in in the late 1920s in the Soviet Union as an approach to the study and education of children and adults with physical or mental disabilities (Lubovsky, 1974). Presently, many universities in Kazakhstan have departments of 'Defectology' that have similar focus to special education departments in western countries.

(*n*=5) and 'other' (*n*=1). Graduate student ages ranged from 23-51 years (*M* = 37.52, *SD* = 8.73). Thirteen university students (61.90%) reported having no prior knowledge of ABA, six reported having some knowledge of ABA (28.57%), and two did not respond (9.52%). Nine university students reported never having taught a child with a disability (42.85%), four reported teaching a child with a disability once or twice (19.04%), three reported seven full days of teaching (14.28%), three reported 30 days or more (13.63%), and two did not respond (9.52%)

Setting

The assessments and training took place at a local university over a two-week period. The assessments were performed by the researcher and Parent Instructors in individual classrooms or therapy rooms. The training program was delivered by the Parent Instructors in a large room with a conference table. The university students were seated around the conference table and to the side of the room. The Parent Instructor stood at the head of the conference table and displayed the PowerPoint presentations on a large projection screen.

Materials

All manuals and materials described in Phase 1 were also used in Phase 2. Additionally, the 15-item Sentiments, Attitudes and Concerns about Inclusive Education - Revised (SACIE-R) questionnaire was used to assess university student attitudes towards inclusion (Forlin, Earle, & Sharma, 2011). The university students rated the extent which they agreed or disagreed with statements regarding inclusive education on a 4-point Likert scale from 1 'strongly agree' to 4 'strongly disagree'. The scale produces an overall score, as well as a score of three subscales; sentiments, attitudes, and concerns. The revised scales showed good validity in a study by Forlin, Earle, and Sharma (2011) with 542 pre-service teachers from four different countries. Reliability for the subscales sentiments, attitudes, and concerns were calculated to be $\alpha = .86$, $\alpha = .86$, and $\alpha = .70$, respectively.

An ABA and Autism Knowledge Exam was created for use in this study. This exam included 55-question multiple-choice and true/false questions to assess the university student's knowledge of ABA and autism (e.g., "Which is not true about reinforcers: a) everyone has different reinforcers; b) reinforcers can change; c) reinforcers increase the future probability of a behaviour; d) stickers are always reinforcers"). Seven of the 55 questions related to content covered in Session 2, and six questions related to content from Sessions 3-10 (an additional question was added for Session 2 in order test knowledge on a variety of topics related to autism e.g., causes, characteristics). The pre-training, but not post-training exam included the option to answer 'I don't know' to all questions.

Social Validity

A Parent Instructor Survey was used and included both open-ended questions and a Likert scales (e. g., 1 'very unlikely' and 5 'very likely'). Feedback was sought across five target areas: (1) overall program satisfaction, (2) usefulness of the program format, (3) perceived changes in their children and parenting following the program, (4) perceived understanding and ease of use of the program, and (5) suggested improvements to the program. An additional ABA rating form listed each skill with a box for Parent Instructors and university students to indicate 'yes' or 'no' if they felt the skill was useful or not. A university student satisfaction survey included seven 5-point Likert scale questions (e.g., 1 'very difficult' to 5 'very easy') assessing the acceptability of the training and one open-ended question eliciting feedback on adaptions to future iterations of the course.

A Student Survey included seven, Likert scale questions (e.g. 1 'very positive' to 5 'very negative') and one open-ended question. The Likert scale questions assessed the overall acceptability, usefulness, and satisfaction with the course. The open-ended questions solicited both positive and critical feedback on the course.

Procedure

Written informed consent was obtained from the university students. One session was taught each day and lasted approximately one hour, except for Sessions 10 and 11 which were shorter (30 minutes) and taught together in a combined lesson. The presentations were given in a large room with a table and chairs and a projector for the PowerPoints. A flowchart detailing the steps of Phase 2 can be found in Table 7.3.

Pre-training assessments

In Session 1, the university students completed the knowledge exam, SACIE-R and the pre-training skills assessments. The skills assessments were administered by the researcher and the Parent Instructors. The researcher and Parent Instructors read the same scenarios that were used in Phase 1 to the university students and provided them with a copy of the component checklists. Either the researcher or the Parent Instructor played the role of the child. The university students were given all the necessary materials and instructed to complete the skill to the best of their ability. If they were not familiar with a skill, they were instructed to say ‘pass.’

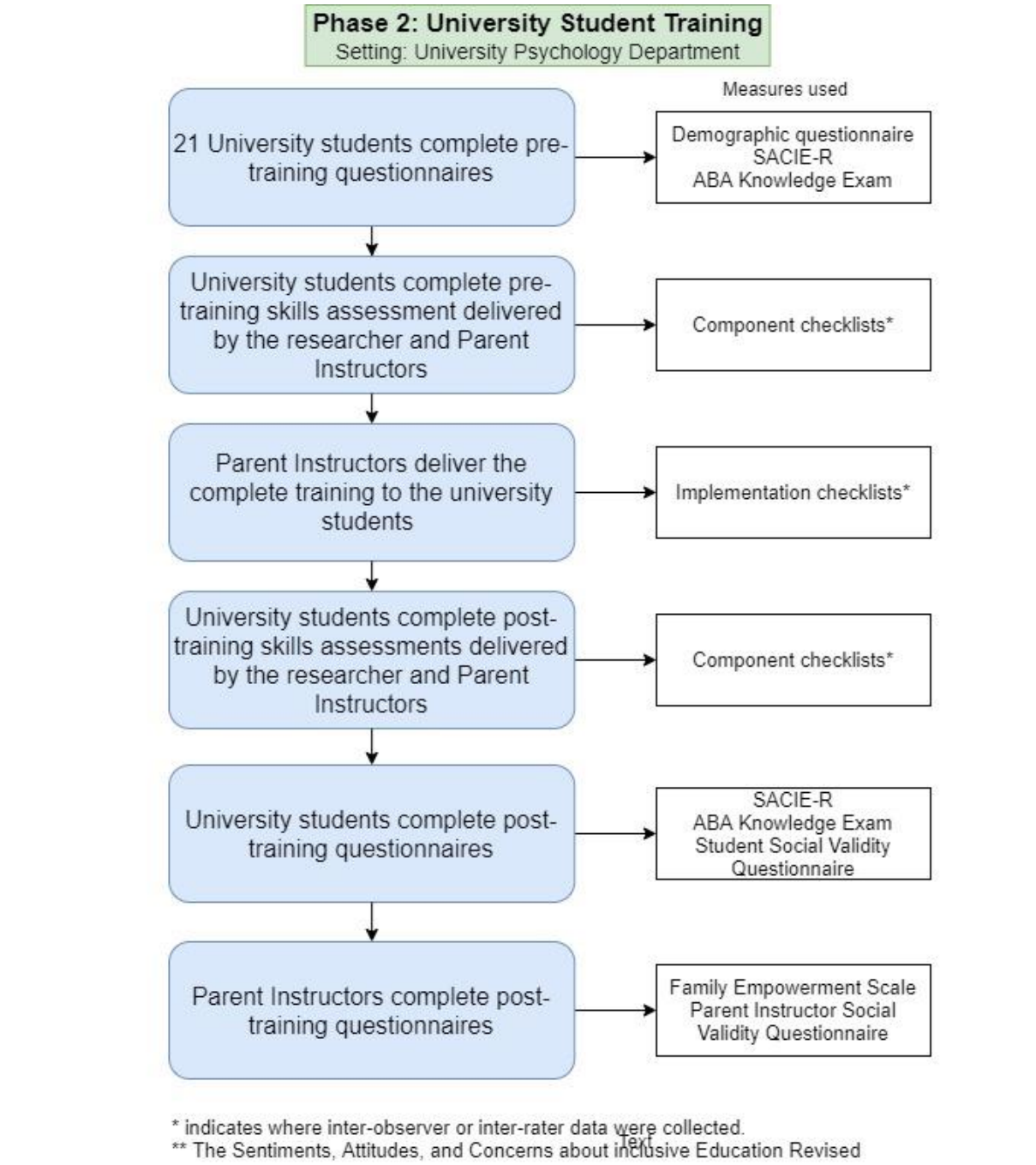


Figure 7.3. Flowchart of Phase 2 procedures.

Training

For Session 2, the Parent Instructors provided a brief description of autism (as prepared by the researcher) followed by small group discussion with one Parent Instructor describing their child to a small group of university students, followed by an interactive discussion. Sessions 3-10 focused on teaching the selected ABA skills using BST. Each session lasted approximately one hour and was delivered by two Parent Instructors. For Sessions 3-10, the students completed the pre-class reading assignment as the first step of BST, the *instruction*. At the beginning of each session the Parent Instructor provided a brief, scripted PowerPoint lecture serving as the second half of the *instruction*. The Parent Instructor then played a video model and/or demonstrated the skill, providing the *model.* Following the model, the university students *rehearsed*, or practiced, the skill with one another. After the *rehearsal*, the Parent Instructor provided individual and group *feedback* until the university students were able to implement each skill accurately. After each session, the Parent Instructors completed the implementation checklists to assess treatment integrity.

Post-training assessments

Following the training, the university students completed the SACIE-R, knowledge exam, skills assessment, and student social validity survey. The skills assessments were conducted in the individual rooms at the university. Once again, the researcher and parent instructors provided the students with component checklists and materials to implement each strategy. The same scenarios were read and either the parent or researcher played the role of the child. The university students were told to implement each skill to the best of their ability. They were not given the option to 'pass'. After the skills assessment, the Parent Instructors completed the FES and parent social validity survey.

Procedural integrity and rater reliability

Implementation checklists were completed independently by Parent Instructors for sessions 3-11 to assess procedural integrity. Overall integrity was 95.5%. The checklists were separated into two sections; instructor objectives and student objectives. Procedural integrity for achieving instructor objectives was 100% on all sessions except for Session 10, which was 82%. Student objectives achieved were 100% for Sessions 3, 5, 6, 7, 9 and 11. Integrity was 94% for Session 4, 80% for Session 8, and 63% for Session 10 (M = 93.00, SD =12.31).

Skills assessment scores were collected by scores were collected by the researcher and a trained assistant for 32% of pre- and post-training skills assessments (131 individual 'skills' scores) A two-way random-effects test was run to assess interclass coefficients. A high degree of reliability was found between the two raters for both pre- and post- raining assessments. The measure ICC was .994 with a 95% confidence interval from .992 to .996 ($F(131, 131)= 178.715$, $p<.001$).

7.2.2 Results

Analytic Approach

An exploratory data analysis (EDA) including visual inspection of the data, skewness and kurtosis statistics and Kolmogorov-Smirnov (K-S) tests of normality indicated that the data was not normally distributed for any measure. Non-parametric analyses were therefore conducted for the main analyses. This approach was applied to all measures with all tests being two-tailed.

Student pre- and post-test skill assessment scores

The university students' pre- and port-training skill assessments scores were analysed. Two-tailed Wilcoxon tests were performed to compare pre- and post- training skills assessments score. Five university students were absent from the pre-training assessment and subsequent pre-training score were unable to be obtained. One-way ANOVAS were run for

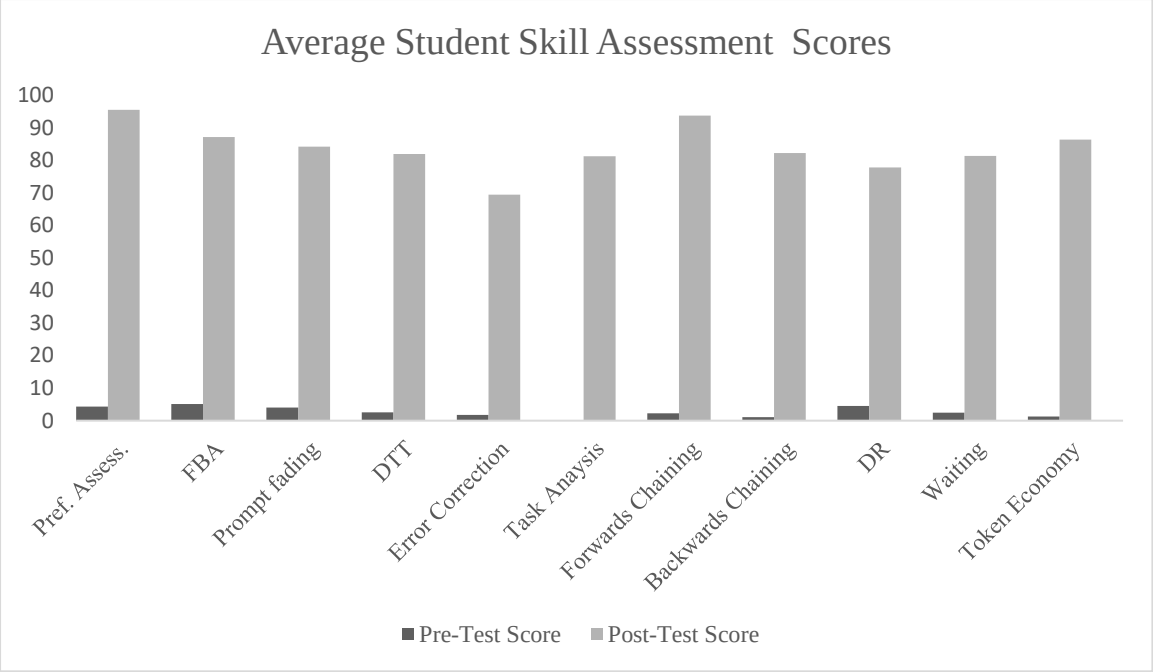
age, years of undergraduate study, gender, and initial attitudes. All results were highly non-significant (all ps > 0.85), meaning that we can assume these university students would have similar pre-test scores to the rest of the sample. Since none of these university students had any previous training or experience in ABA, they were assigned the average pre-training score for each skill. This allowed their post-test scores to be included in the analysis. University student pre-test skill assessment scores were low (M = 6.16, SD = 3.20). Post-test scores resulted in an increased performance (M = 85.45, SD = 6.49), for a significant gain of approximately 81 percentage points. Significant improvements were found across all skills at post-test, ps<.01. The results are displayed in Table 7.3. Average pre- and post- training skills assessment scores for each skill are displayed in Figure 7.4.

A secondary analysis was performed excluding the five participants with missing baseline data. The remaining 16 student pre-test skill assessment pre-training (M = 5.99, SD = 3.07) and post-training scores (M = 83.36, SD = 15.55) were similar to those found when the average pre-training scores were assigned to the five students. This finding justifies the inclusion of those five university students in the rest of the analysis.

Table 7.3

Results from Wilcoxon Test for Pre- and Post-Training University Student Skills Assessments

			Pre-training score		Post-training scores	
Skill	Z	Significance	Mean	SD	Mean	SD
Preference assessment	-4.038	< .01	7.47	14.33	95.57	10.29
Functional behaviour assessment	-3.993	< .01	10.11	11.30	87.15	15.37
Prompt fading	-4.035	< .01	9.59	5.89	84.29	14.16
Discrete trial teaching	-3.937	< .01	7.38	13.37	91.10	12.07
Error correction	-3.839	< .01	7.42	18.84	73.00	15.25
Task analysis	-3.963	< .01	1.45	5.41	81.25	22.76
Forward chaining	-4.002	< .01	3.19	7.39	93.75	13.75
Backward chaining	-3.669	< .01	.26	.48	88.24	17.94
Differential reinforcement	-3.934	< .01	9.07	11.12	77.85	18.45
Waiting	-3.929	< .01	7.76	11.92	81.35	16.91
Token economy	-3.963	< .01	4.09	8.55	86.40	13.63



Note. FBA, functional behaviour assessment*, DTT* discrete trial teaching*, DR,* differential reinforcement.

Figure 7.4. Average university student pre- and post-training skill assessment scores.

Comparison of ABA Knowledge Exam Scores at Pre- and Post-Training

There was a significant difference in pre-test scores (M = 42.35%, SD =14.01) and post-test scores (M = 81.24, SD =3.05); $t(20)$= -12.44, p< .001. There was a mean gain of 38.89 percentage points from pre- to post- training. These results suggest that the training program can successfully teach university students basic information on ABA and autism. Scores for questions related to each session range from 59.59% (session 3) to 94.57% (session 2; see Table 7.4). Sessions 3 and 7 each had one question score extremely low at post-test (only two respondents correctly answering) and Session 6 had two low scoring questions at post-test (three and six responding correctly).

Table 7.4

University Student Post-Training Scores Per Session Content on the ABA Knowledge Exam.

Session	2	3	4	5	6	7	8	9	10
Mean	94.57	59.59	91.83	93.57	68.16	68.33	88.00	83.16	84.00
Standard Deviation	6.38	32.58	4.48	4.42	34.69	36.68	12.42	14.49	23.35

Comparison of Family Empowerment Scale (FES) Scores at Pre- and Post-Training

A two-tailed Wilcoxon test was conducted to compare pre-training and post-training FES scores. Individual item responses are displayed in Table 7.5. There was a significant difference in pre- and post-training scores, Z= -2.19, p = .028 (pre: M =3.91, SD = 0.45; post: M = 4.20, SD = 0.48). A Wilcoxon test was also performed comparing scores on the three subscales, Family, Service System, and Community/Political at pre-and post-test. There was a significant difference in the pre- and post-training scores for the Family scale; Z= -2.04, p = .041 (pre: M = 4.05, SD = 0.36; post: M = 4.30, SD = 0.46), indicating that the Parent Instructors reported significantly greater feelings of empowerment in this domain following training. There was a significant different in scores on the Community/Political scale at pre- and post-training, indicating that Parent Instructors reported greater empowerment in the community/political domain at post-training; Z = -2.37, p = .018 (pre: M = 3.36, SD = 0.73; post: M = 3.80, SD = 0.65). There was no significant difference between Service Systems scale scores at pre- and post-training; Z = -1.70, p = .088 (pre: M = 4.32, SD = 0.46; post: M = 4.49, SD =.45).

Comparison of Student Sentiments, Attitudes, and Concerns Regarding Inclusive Education at Pre and Post-Training

A two-tailed Wilcoxon test was conducted to compare pre-training and post-training SACIE-R scores. There was no significant difference in the pre- and post-training scores; Z =-.34, p =.73 (pre: M = 2.67, SD = 0.36; post: M = 2.68, SD = 0.34). A Wilcoxon test was also performed for the three subscales, Sentiments, Attitudes, and Concerns. There were no significant differences in the pre- and post-training Sentiment, Attitude or Concerns subscales (all ps >.05).

Social Validity

Parent Instructor Surveys

Feedback on training programme structure. All Parent Instructors responded to the open-ended questions regarding the most and least helpful aspects of the training. Three Parent Instructors stated the practice/role playing of skills was the most useful, two Parent Instructors stated all parts were useful, and one said that the two sessions focusing on communication skills were the most useful. Only three Parent Instructors completed the section on the least helpful aspect of the training, with two stating the theoretical basis to ABA and one stating that she found the history of autism the least helpful sections. However, another Parent Instructor noted that the theoretical component was 'the foundation for everything.'

Parent Instructors also rated the helpfulness of the different components of the training package. Results are displayed in Figure 7.4. All training components were rated either very helpful or helpful. The Parent Instructors found the video examples, practice/role play sessions, and the instructor manuals to be the most useful components of the training, with all components rated very helpful. The Parent Instructors found the implementation checklists and the component checklists to be the least helpful, but they were still rated very highly (M = 4.57/5).

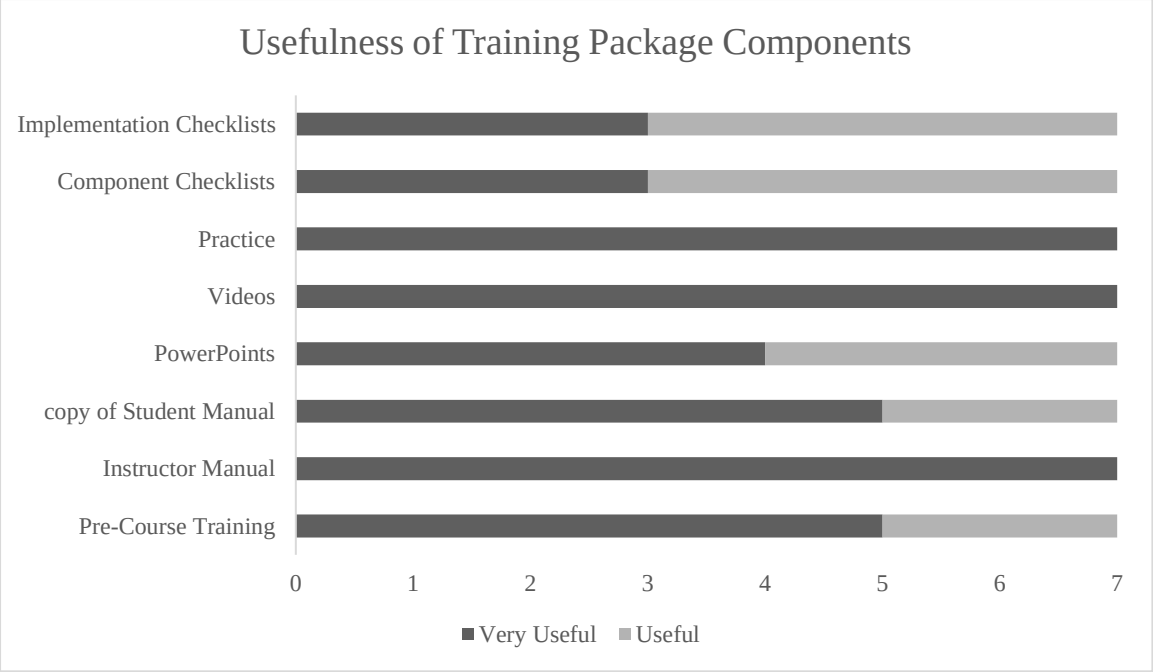


Figure 7.5. Parent Instructor rating of training package components.

Feedback on the feasibility and acceptance of programme. Two open ended and four 5-point Likert rating scales questions were used to assess the overall ease of the program. When asked how easy it was to understand the concepts of ABA, all Parent Instructors reported that it was 'easy' or 'very easy'. However, two Parent Instructors noted that there were some difficulties with the translations of the manual. When asked how easy it was to learn the skills and use them with children, six Parent Instructors responded. Four stated it was easy, while two reported they had not started using them with their child. On the 5-point Likert scale, from 1 'very hard' to 5 'very easy'. Two Parent Instructors indicated that is was it 'very easy' to understand ABA, while five Parent Instructors rated it 'easy' (M = 4.20). Six Parent Instructors found it 'easy' and one thought it was 'very easy' to teach the course (M = 4.14). When asked how appropriate it is to use ABA with children with autism, six responded 'very appropriate' and one responded 'appropriate' (M = 4.85). Two Parent Instructors felt 'very confident' and five 'confident' to implement the ABA strategies with their own children (M = 4.28). Finally, all responded that they were 'very likely' to recommend the training to a friend (M = 5.00).

Feedback for programme modifications. Two open and one closed ended question were used to elicit suggestions for modifications to the training programme. The Parent Instructors reported wanting more video examples, information on how to react when children make mistakes, and how to cope with challenging behaviors. It was also requested that the instructor manual also include the glossary/dictionary in the student manual. When asked for any further suggestions, only one Parent Instructor responded:

> "Thank you for this very interesting and useful training. I think this training will be very useful for every parent and future specialists. The students enjoyed the practice sessions. Some teachers were really engaged and practiced a lot. Other teachers did not want to practice because they thought it was not necessary. After they were encouraged to practice, they did. I had to insist that the teachers' practice. I think the teachers thought that they had more qualifications and knowledge than the mothers. Although some teachers were inspired. Especially teachers who currently work with

> children with autism. Those who didn't want to practice the skills were university teachers. If it is interesting for the teachers, they will practice. The students were very active. During the lessons the teachers sat with each other and the students sat with each other."

She continued to state that she found it useful to review the vocabulary words at the beginning of each lesson. She also said that the university students were very vocal regarding which sessions they found useful and which they did not. She reported that the students found the practice sessions much more useful and interesting than the history of autism. She stated that the master students who were currently working with children with disabilities found the training particularly useful. Finally, she said that while it was good to be able to answer questions based on her own experience, sometimes she was unable to answer a question about a child who was very different to her own.

Feedback on perceived changes. Three open ended questions assessed maternal perceptions of any changes for themselves (e.g., parenting style, communication) or their children. Two Parent Instructors noted changes (improved communication and motivation), four reported that they now understand ABA methods and used them with their child, while another Parent Instructor stated that her child is more independent and that she understands her better. When asked if there were any changes in their level of interest in their child's education, six Parent Instructors responded. Two stated that they have a better understanding and one expressed a desire to become more involved, but there were barriers. One Parent Instructor reported wanting her child to have ABA lessons and another reported a desire to become an ABA specialist herself. When asked if they noticed any changes in their child's ability to communicate, six Parent Instructors responded. One said there were no changes yet. Another reported that she has a better understanding of how to effectively communicate with her child. One Parent Instructor reported that her child is *"using more words now due to ABA*", and two reported that their children began using PECS. One Parent Instructor stated that her child's ability to understand and learn has increased.

University Student Surveys

Most university students rated the ease of learning ABA strategies as 'neutral' (71%). More than half of the university students (66%) found the practice/ role play activities to be very useful and just over half (57%) found the pre-class readings to be very useful. Most of the university students (81%) said that the parent's role as instructors on the course had a very positive impact on them. Half of the university students (52%) reported that they were 'very likely' to use the ABA strategies in their future jobs, and 57% of student felt 'very prepared' to use the ABA strategies. Almost all the university student 87%) said they would 'definitely yes' recommend this course to other students. There were no negative responses to any survey items from the university students.

In the open comments section, five university students responded:

> "I liked the training. It was interesting to listen to the mothers who have children with autism. They have great knowledge about the autism- situation."
>
> "I've always had a desire to visit ABA training. Once I heard that there was an opportunity, I was happy. The training was really good. The moms did their best. They also answered all the questions. I would like to have ABA training again, but with a higher level."
>
> "This training was very useful for people who have decided to be in this field. Some moms should have been more prepared, not everyone was ready."
>
> "The training was great. The presentation of the material was interesting. The speakers showed a deep understanding of the material/topic. There were a lot of real-world applications/ examples. The presentation was interesting due to different speakers. The exercises improved our skills."
>
> "Thank you! We're looking forward to continuing studying!"

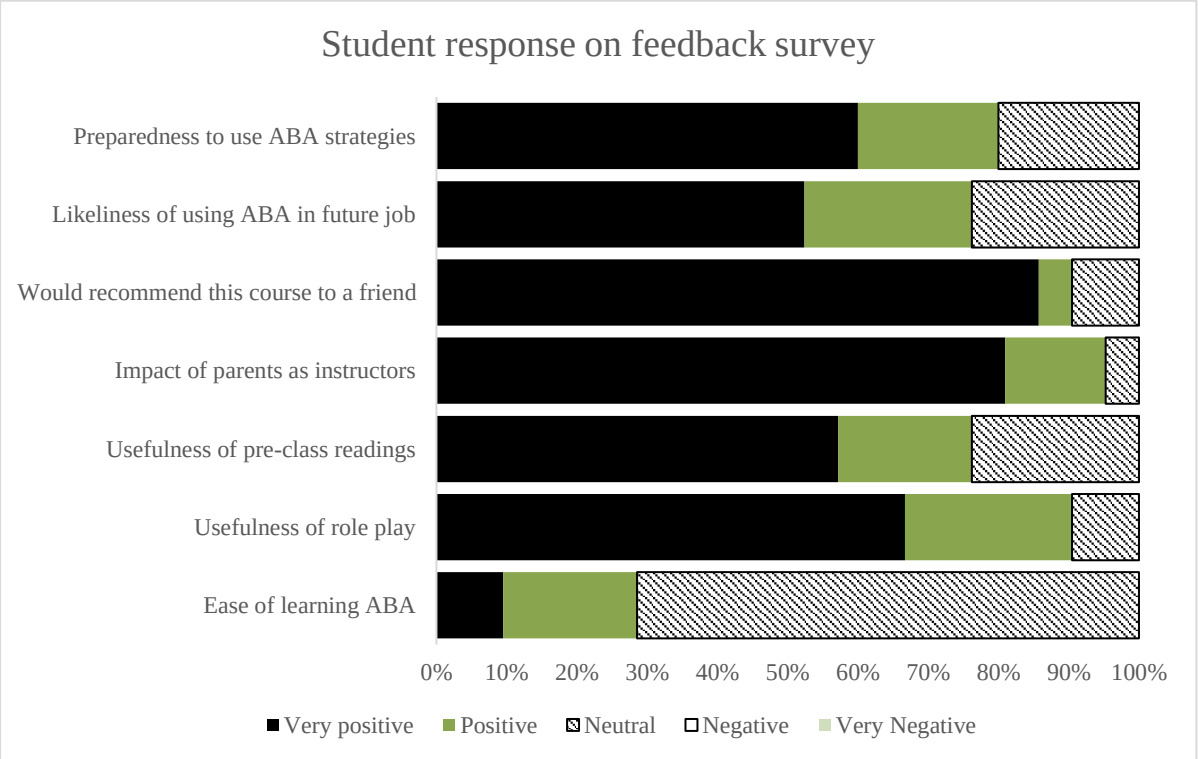
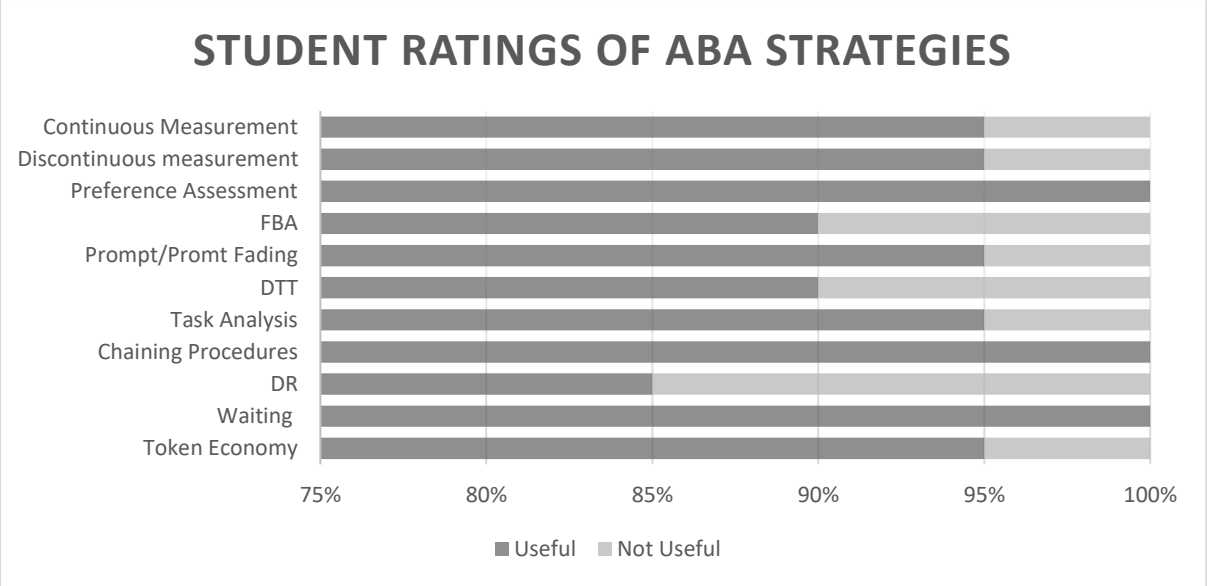


Figure 7.6. University student responses on feedback survey.

ABA Rating Scale

Both the Parent Instructors and university students were given a rating form for the 11 ABA strategies with the option to rate the strategy either as ‘useful’ or ‘not useful’. Results are displayed in Figure 7.7. All Parent Instructors rated every strategy useful. Of the university students who responded (n = 20) preference assessments, chaining and waiting procedures were rated the most useful (100%), followed by continuous measurement, discontinuous measurement, prompt/prompt fading, task analysis, and token economy (95%). Most university students rated FBA useful (90%) and 85% found differential reinforcement to be useful.



Note. *FBA*, functional behaviour assessment; *DTT*, discrete trial teaching; *DR*, differential reinforcement.

Figure 7.7. University student rating of individual Applied Behavior Analysis strategies.

7.3 Discussion

Results from this study suggest that a manualized, BST training program is an effective, feasible, and acceptable form of training. Phase 1 parent training was successful in teaching the Parent Instructors new ABA strategies; most Parent Instructors accurately demonstrated each skill on their first or second try, with only a few instances of needing up to four attempts. Phase 2 university student training was successful in teaching new skills to undergraduate and graduate students. The university students had no prior training or experience using ABA skills and scored low on the pre-training assessments. Post-training, assessment score improved an average of 81 percentage points for each skill. The training was also successful in improving student scores on an ABA and Autism multiple choice knowledge exam.

This study builds on previous BST research that used a pyramidal training approach (Parsons, Rollyson, & Reid, 2013). However, this was the first study to determine if this approach would work when training individuals who did not have previous mastery in the skills taught. Consistent with previous research (Heitzman-Powell, Buzhardt, Rusinko, & Miller, 2014), the Parent Instructors quickly learned to implement the ABA skills accurately. The Parent Instructors demonstrated the ability to deliver the training with high fidelity (63-100%). However, they reported struggling with the advanced topics (e.g., stimulus control, behavior reduction interventions) and having limited practical experience. After the completion of the study, the researcher held a question and answer session to resolve any remaining quandaries. The addition of a post-training question and answer or a mid-training question and answer session with a BCBA would help to answer questions on difficult topics and support the novice instructors delivering the training.

The total training time was relatively brief, taking 21 hours for Parent Instructors, and 10 hours for the university students. It should be noted that roughly a quarter of the training time for the Parent Instructors was for the purposes of translation. Therefore, this training

program provides a brief, cost-efficient solution to training provision where the availability or resources necessary to have a highly qualified professional are not available. It also provides a training program for individuals living in remote areas with restricted internet access, such as Kazakhstan. This is also the first BST study to use parents as instructors. The Parent Instructors were highly satisfied with the training and showed significant gains in self-reported empowerment. These findings build on previous research demonstrating the benefits of embedding parents as co-instructors in college courses (McBride, Sharp, Higgins-Hains, & Whitehead, 1995).

The university students, however, did not display significant changes in their attitudes toward inclusion. A recent systematic review of interventions targeting pre-service teachers' attitudes towards inclusion found that eight out of the eleven studies that combined classroom information with practical field experiences were able to produce statistically significant improvements in attitudes towards inclusion using instruments similar to the one used in this study (Lautenbach & Heyder, 2019). The additional of a practical element to the training programme described in this study may help improve attitudes towards. Additionally, almost all of the studies in the review that showed improvements in attitudes were conducted over an entire semester. Future studies extending the present course from two weeks to a full semester may yield larger shifts in university student attitudes.

Incorporating parents in university training programs may be one solution for concerns that pre-service teachers are ill-equipped and under-prepared to communicate with parents and build strong parent-teacher relationships (Hedges & Gibbs, 2005; Murray, Curran, & Zellers, 2008). The university students were satisfied with Parent Instructors leading the course and enjoyed hearing their stories about their own children, consistent with the existing literature identifying the benefits of parents as instructors in university training courses for pre-service professionals (Collier, Keefe, & Hirrel, 2015; Murray, Curran, &

Zellers, 2008). However, one student noted that some Parent Instructors could have been more prepared. Following the study, the students requested a session with the researcher to answer additional questions that the Parent Instructors were unable to answer. This suggests that while the Parent Instructors were able to teach the program and ABA skills, their lack of in-depth knowledge limited the information they were able to deliver and the amount of questions they were able to thoroughly answer. This suggests that ongoing support from an experienced behaviour analyst is needed.

These finding should be considered in light of the recent BACB changes to the RBT training requirements (BACB, 2018). While this study was not specifically an RBT training package, it did include many items on the task list and was designed for entry-level practitioners. The changes indicate that the RBT training courses can be delivered using a tiered system; an 'assistant assessor' may deliver the training as long as it is overseen by a 'responsible assessor'. The responsible assessor must hold a BACB certificate, however, the assistant assessor is not required to hold specific qualifications or credentials. Thus, this study provides an example of how an assistant assessor could be trained to deliver an RBT training accurately while also noting the importance of the responsible assessor to provide clarifications and guidance on more complex topics.

The findings from this study should be interpreted with the following considerations Pre-training skills assessment data was not collected for five participants. The performance of university students in implementing taught skills were only assessed via a role-play scenario. It was not determined whether or not the skills gained in this course will generalize to with the university students' actual instruction with children with disabilities. Additionally, no long-term follow-up data were collected, therefore it is uncertain if the university students retained the skills learned in this short course. Previous research has found that without specific plans for monitoring maintenance, performance skills accurate implementation of

ABA procedures decreases over time (McSween & Matthews 2005; Mozingo, Smith, Riordan, Reiss, Bailey, 2006; Williams, Vittorio, & Hausherr, 2002).

Finally, several researchers have raised ethical concerns about the provision of short-term training in locations with limited access to ongoing support from a highly qualified professional. Short courses in ABA may over-simplify content and lead professionals to become overconfident about their level of knowledge and expertise in behavior analysis (Kelly, Martin, Dillenburger, Kelly, & Miller, 2019; Noone & Chaplin, 2017). Additionally, it has been suggested that without a strong conceptual foundation, ABA training can easily become a 'bag of tricks' (Miltenberger, 2018). The potential exists that one could attending a training, such as the one described in the study, receive a certificate of participation and subsequently identify themselves as an ABA 'expert'. However, the treatment offered by this 'expert' is unlikely to reflect true ABA services and may perpetuate beliefs that ABA is not an effective treatment. Careful considerations of the availability of professionals to provide post-training support should be undertaken prior to delivering short-term training courses.

Given the results of this study suggest that once manualized, BST is an effective and time-efficient methods for preparing university students to implement EBPs. It would also be of benefit to assess the feasibility of embedding a BST into a full, semester-long university course. This would help determine how well this intervention could integrate into a traditional university class schedule. Future studies should investigate to what extent skills learned during a role play BST program will generalize to use with children or adults with disabilities. Additional follow-up research should to determine how well the skills learnt in this short-term training are maintained over a longer period time.

7.4 Implementation

The implementation of novel programs or interventions should be carefully considered. If the independent variable is not applied in the manner it was designed to be, it is difficult to determine whether poor outcomes are due to the intervention not having an effect or to poor delivery of the intervention. Implementation refers to what the intervention consists of when applied in a particular setting (Durlak & Dupre, 2008). Implementation quality refers to the "discrepancy between what is planned and what is actually delivered" (Domitrovich et al, 2008, p. 3).

A meta-analysis examining the relationship between implementation fidelity and program outcome found that programs that were implemented with high fidelity resulted in a mean effect size two to three times higher than poorly implemented programs (Derzon Sale, Springer, Brounstein., 2005). Another review of 483 studies of implementation found that the level of implementation is an important factor for program outcomes (Durlak & Supre, 2008). Researchers have noted that 100% implementation is impossible to achieve, so one should expect some drift in implementation. However, implementation between 60%-80% appears to lead to positive outcomes (Durlak & Dupre, 2008). Some research even suggest that slight program modifications made during implementation to meet the needs of that particular setting can improve program outcomes (Blakely et al. 1987; McGraw et al. 1996; Kerr et al. 1985).

With evidence suggesting the importance of implementation, researchers have identified a number factors affecting implementation, including community level factors, provider characteristics, characteristic of innovation, organizational capacity, and factors related to the prevention support system (resources for training; Durlak, 2015; Fixxen et al., 2005; Greenhalgh et al., 2005). Related to these factors is the compatibility and adaptability

of a program within a specific setting (Berman & McLaughlin, 1976). However, few studies have assessed the relationship between these factors or evaluated the relative influence of each factor on implementation outcomes (Durlak, 2005).

Few studies have evaluated the impact of different delivery agents, but the research is limited and mixed. Oftentimes, the researchers themselves are the ones delivering the training and thus are able to implement the program with high fidelity. This, however, does not provide insights into the actual feasibility of implementation by non-experts. Research focusing on the different delivery agents for school-based training have been mixed; some find that have an outside specialist enter the school to deliver the program as advantageous, while others have found that training teachers to deliver the program to be more beneficial, while other studies found no difference (Ellickson & Bell, 1990; Rohrbach et al., 2005; Spoth et al., 2007).

Current research suggests new programs and interventions should carefully plan and assess implementation. The main study in this thesis monitored and evaluated implementation based on the five critical aspects identified by Dane and Schneider (1998). These factors include fidelity, dosage, quality, participant responsiveness, and program differentiation.

7.4.1 Fidelity

Fidelity is the extent to which the intervention corresponds to the originally intended program (a k a adherence, compliance, integrity, faithful replication). This was assessed throughout the training programs using the implementation checklists (see Figure 6.5). The implementation checklists were first used during phase one during the *instruction* when the researcher initially delivered the training to the Parent Instructors. Fidelity was 100%. This high level of integrity can be attributed to the fact that the researcher created the training and their level of subject matter expertise and professional experience with public speaking and training.

The checklists were used once again in phase one of the study during the *rehearsal*. Each Parent Instructor took turns delivering the sessions of the training. At the end of each session, the researcher independently completed the implementation checklist. The researcher then instructed the Parent Instructors to complete the checklist and the results were discussed. During this process the researcher explained the elements of the checklists to the Parent Instructors and provided feedback to the Parent Instructors if they were not using the checklists properly. Fidelity was very high for these sessions, with all sessions except for Session 10 (which was 89%) getting 100% accuracy.

The same implementation checklists were used in Phase 2 during the university student training. The checklists were completed by two Parent Instructors; the Parent Instructor delivering the training and the additional Parent Instructor who was there for support. Overall integrity was 95.5%. Integrity for instructor objectives (98.3%) was higher than student objectives (93%). For both student and instructor objectives, Session 10 had the lowest integrity score. Session 10 also had the lowest score during the rehearsal portion of phase one and the skills taught in Session 10 took the longest for the Parent Instructors to obtain the 100% accuracy mastery criteria during the *in-session checks.* Additionally, the Parent Instructors added a brief discussion at the beginning of each session to discuss the key terms. This was not a part of the intervention, but the Parent Instructors found that it was a useful activity and therefore included it in every session. This addition did not impact implementation scores.

It is likely that the high level of fidelity throughout the training was due to the scripted training manuals, which have previously been shown to improve treatment fidelity (Schinke, Gilchrest, & Snow, 1985). Most objectives included in the implementation checklists would be met as long as the instructor read the script. The design of the parent training program in Phase 1 may have also contributed to the high levels of fidelity, as training has been linked to

greater integrity (Perry, Murray, & Griffin, 1990; Ross, Lupecker, Nelson, Saavedra & Hubbard, 1991). Parent-reported integrity scores should be viewed with caution. The researcher was not able to verify these scores and it is possible that the Parent Instructors could have inflated the scores due to social desirability bias and not wanting to show that they did not implement the intervention properly (Pentz et al., 1990). In order to prevent this, the Parent Instructors were specifically instructed to be honest with the checklists and the researcher explained why it was more important to be truthful rather than to be 100% accurate, however it is still possible that scores were inflated.

7.4.2 Dosage

Dosage refers to how much of the original intervention was been delivered (quantity, intervention strength). The dosage of the present study was high, but with some modifications. The intervention was originally planned to take place over eight weeks. Phase 1 initial parent training and pre-training assessments of the university students was planned to occur over a two-week period. Following this, Phaser 2 university student training sessions were designed to be deliverer two times a week for six consecutive weeks. This delivery was chosen to lessen the burden on the Parent Instructors and to more closely mimic a typical university class schedule. However, after the parent training and during the pre-training assessments of the university students, the head of the university department suggested a change in schedule. Instead of twice a week for six weeks, she proposed that the training take place once a day for two weeks. The university students agreed that this schedule would best for them. To fit the context, the intervention schedule was changed, and a more intense training program was delivered, though the number of hours of delivered did not change.

Of the original sessions prepared, all but one section was delivered during the parent training and university training. Session 10 Section 2 was removed by the researcher during the parent training in Phase 1. This was the last section with a practical activity; however, this

practical activity was not an activity that was planned to be assessed as part of the research. This section was taken out after due to limited training time left and the relevance of the activity. The activity removed detailed a group behaviour management strategy, however, this strategy is more applicable to older children than younger ones. When the activity was described to the Parent Instructors and the reason for suggested removal given, the Parent Instructors agreed that is was appropriate to remove the activity. This section was not presented to the university students.

7.4.3 Quality

Quality refers to how well different program components have been conducted (e.g., are the main program elements delivered clearly and correctly?). Though not specifically asked, in the open-ended response questions several students noted the positive impact of having the parents serve as instructors. One student, however, noted that not all of the Parent Instructors were prepared. This could have impacted the quality of that session. The Parent Instructors also noted that while they were able to share their own experiences, they were unable to provide examples from other children. They reported that when the students asked complex questions, they were unable to provide satisfactory responses. These results support previous research that has identified ongoing supervision as an essential element of high quality implementation (Harchik, Sherman, Sheldon, & Strouse, 1992; Peterson, Mori, Selby, & Rosen, 1988).

7.4.4 Participant responsiveness

Participant responsiveness refers to the degree to which the program stimulates the interest or holds the attention of participants (e.g., are university students attentive during program lessons?). The data from the study suggests that participant responsiveness was high overall. All seven Parent Instructors that began Phase 1 participated in the training in Phase 2. All 21 university students that opted to participate in the study completed the full course and

post-training assessment. Those that completed the study participated on average in 9.6/10 sessions (range 8-10). When asked, university staff members indicated that this attendance rate is in-line or slightly above of typical university class attendance in Kazakhstan. It was requested that the university students be given certificates at the end of the study to indicate their participate in the research project. Certificates were also provided to the translators upon request. The university students appeared to be very motivated by the certificates. It is hypothesized by the researcher that the certificates were influential to the high rights of attendance.

Written feedback from the Parent Instructors and university students suggest the training programme was valuable and useful. The results from the social validity questionnaires indicate that the Parent Instructors found the parent training described in Phase 1 to be adequate to prepare them to deliver the course. Though initially nervous, the Parent Instructors felt well-prepared to deliver the training and reported it being a positive experience. Many of the Parent Instructors indicated an interest in learning more about ABA and gaining more experience. Overall, they stated that they were grateful for the training as there are not many opportunities for them to learn new ways to work with their children. The study required a substantial time commitment from the parents. It is unclear if the Parent Instructors would have dedicated their time to this training if other training that were less time consuming were available.

The university students also indicated that they found the training to be useful in their social validity responses. One Parent Instructor indicate that the younger university students were more engaged than the older students who were working as teachers while enrolled in graduate coursework. The Parent Instructor hypothesized that these students thought they had more experience and expertise than the mothers and, therefore, were not as eager to participate in the hands-on practice sessions. This aligns with results from the qualitative

study in Chapter 4 of this thesis where the Parent Instructors indicated that the younger students were more open to learning new techniques.

7.4.5 Program differentiation

Program differentiation involves the extent to which a program's theory and practices can be distinguished from other programs (program uniqueness). In the context of Kazakhstan, this is the first training that has embedded parents as instructors into a university setting. It was also one of few training courses on ABA available in the country. It was the first opportunity most of the university students and parents have had to learn about the principles of ABA. It was also the first time a Board Certified Behavior Analyst had visited the region of Eastern Kazakhstan. This geographic location does not have many training or research opportunities as most of these activities take place in the major cities of Nur-Sultan and Almaty. The uniqueness of this opportunity may have contributed to the high level of interest in the study.

A substantial amount of research investigating BST has been performed (see Chapter 2, Part 2). Though many of the studies had parents as participants, this is the first study that used a pyramidal approach to train parents to deliver BST to university students. This study provided a unique opportunity for parents to not only gain new ABA skills, but to develop professional skills to train other to use ABA procedures. This was the first study to use BST in a class-wide setting. Previous research studies have only delivered the training to up to four participants at a time (Sawyer et al., 2017). This was the first study to determine the efficacy of training skills to a large group at the same time. This was also the first study to create and utilize a scripted, manualised BST program. The scripts and materials provided in the student and instructor manuals allowed for the training to be delivered with high fidelity by non-experts.

8. Follow-up Study

Research Aim 4: Assess and evaluate the feasibility, acceptability, and efficacy of the training programme.

Abstract

Behavioural skills training (BST) has a growing evidence base for its use in training professionals to implement applied behaviour analysis strategies. However, it can be time-consuming and there is limited research on its use in group training formats. Chapter 7 in this thesis assessed the efficacy of a manualized BST training programme to teach university students to implement eleven evidence-based practices (EBPs). Results showed that participants improved an average of 81 percentage points from pre- to post-training. The results from this study are promising. However, the study was not able to determine whether or not skills learned during role-play scenarios would generalize to use with children with autism and developmental disabilities. The follow-up study in this chapter evaluated the effectiveness of the manualized BST training programme delivered to a group of seven tutors. Training was provided via role-play scenarios, as it was in chapter seven. Post-training skill assessments were performed in- situ with children with autism and developmental disabilities. Tutors in this study improved an average of 47.54 percentage points for each skill. Results suggest that skills taught during role-play scenarios were effectively transferred children with autism.

In Kazakhstan, there is an overall lack of services, schools, and highly qualified professionals to work with children and adults with autism (An & Chan, 2018). This is particularly problematic from families living in rural areas, who are historically underserved as compared to families living in urban areas (see Chapters 3 and 4). Due to these circumstances, it is critical to systematically plan how to train various professionals who are well positioned to support children with autism and their families in Kazakhstan. Interventions based on the principles of applied behaviour analysis (ABA) are commonly used in the treatment of autism. There is a growing research based for the effectiveness of behavioural skills training (BST), a systematic approach to training individuals to implement ABA strategies and procedures (Parsons, Rollyson, & Reid, 2013).

BST consists of 4 steps: Instruction (either verbal or written), model, rehearsal, and feedback. BST has been shown to be more effective than traditional didactic training but can be time consuming to implement (Parsons & Reid, 2012; Petscher & Bailey, 2006). A manualized BST protocol was created in Chapter 6 of this thesis to decrease the preparation time for the instructor delivering BST. The main study in Chapter 7 delivered the training in a group format to 21 undergraduate and graduate students at a university in Eastern Kazakhstan. The training was delivered over a two-week period by mothers of children with autism who had been previously trained by the researcher to implement the skills and use the training protocol. The study found that the manualized BST course was effective for teaching skills assessed in a role-play scenario but did not assess whether the university student's learning would generalize to their use with children.

The aim of the present study is to assess whether the skills taught in a group, role-play BST training program will generalize to new environments and be accurately applied when working with children with autism. This study was completed in a small town in Eastern Kazakhstan, where resources and access to highly trained professionals are scarce. The

success of such a programme could lead to the training of numerous professionals without the high cost of using an international consultant.

8.1 Methods

8.1.1 Participants

Seven tutors who were employed at a local centre that provided educational and recreational services for children with autism and related developmental disorders participated in the study. The tutors were all female, ranged from age 21-23 years old (M = 22.14, SD = 0.63), and recently graduated with a Bachelor of Arts in either Psychology (n = 4) or Defectology[8] (n = 3). All tutors had been employed at the centre since it opened eight months prior. One tutor had previously worked at an autism centre for three months and the remaining tutors had no prior experience working with children with autism. At the onset of their employment, the tutors participated in a two-week training course with a local master-level psychologist. Outside of this, none of the tutors had received any other formal training in ABA or working with children with autism.

The child participants included two girls and six boys whose ages ranged from 4-10 years (M = 6.50, SD = 1.95). All children had a diagnosed language delay, seven participants a diagnosis of autism and one had a diagnosis of developmental delay (note that the child with a diagnosis of developmental delay was too young to receive an autism diagnosis in Kazakhstan; see Chapter 4 for more details). All children attended the centre for weekly educational lessons from the tutors. The lessons mostly consisted of singing songs, coloring, and simple daily living skills. Only one child had received previous ABA interventions (a five-year-old female paired with Tutor 5).

[8] 8 *Defectology* was created in in the late 1920s in the Soviet Union as an approach to the study and education of children and adults with physical or mental disabilities (Lubovsky, 1974). Presently, many universities in Kazakhstan have departments of 'Defectology' that have similar focus to special education departments in western countries.

The training was co-delivered by the primary researcher, a BCBA enrolled in a PhD programme and a Parent Instructor. The Parent Instructor was the director of the centre, who also has child with autism. The director had previous training in ABA, but no formal qualifications in behaviour analysis. She participated in the main study described in Chapter 7, where she received the training programme, rehearsed delivering the training through behavioural skills training, then co-instructed the training course to university students along with six other mothers of children with autism. The Parent Instructor delivered the majority of the training in Russian, while the researcher was available to support and answer any additional questions. The Parent Instructor is a certified translator and was able to translate any questions between the tutors and the researcher.

8.1.2 Setting

The trainings took place at the centre in Kazakhstan where the Parent Instructor and tutors were employed and the children received educational and recreational services. The centre was new and in good condition with several group and individual therapy rooms. Pre-training assessments were conducted in an individual therapy room. The group training sessions were held in a large meeting room with PowerPoint slides detailing the principles and practice of ABA presented on a laptop computer. Post-training assessments were performed in the various group and individual therapy rooms at the centre.

8.1.3 Materials

Manual

Instructor and student manuals described in Chapter 6 of this thesis were used in this study. The training manuals consisted of 11 sessions. Within the 11 session, ten EBPs (henceforth *skills)* were selected based on their inclusion on the BACB's Registered Behavior Technician task and identification by Wong et al. (2013) as the skills with the strongest evidence base and those considered necessary for entry-level therapists (see Table 7.2 for

course outline). The skills taught in this training included preference assessment, functional behavior assessment (FBA), discrete trial teaching (DTT), error correction (EC), differential reinforcement (DR), prompt fading, task analysis, forwards and backwards chaining, and token economy. A description of each skill can be found in section 6.2.2 of this thesis.

For this study, Session 2 was omitted as it covered material that the tutors have already covered during their initial on-the-job training (psychoeducation regarding autism). The Parent Instructor and researcher used the instructor manual and corresponding PowerPoint presentations to deliver the training sessions. Sessions were scripted to ensure a high quality of implementation and adherence to the programme. The script had symbols which indicated when to play the required videos, demonstrate skills, complete activities and assess student performance.

The implementation checklists and component checklists from the main study were also used in this study. The implementation checklists included all tutor and instructor objectives for each module. The component checklists included the essential steps needed for accurate implementation of each ABA skill (see section 7.1.1 for more details). The appendix of the manual included a glossary of terms, sample data collection sheets and component checklists. The manuals were previously translated by local translators, as described in Chapter 6. Minor adjustments were made to the manuals based on feedback provided by students and parent instructors in the main study to clarify discrepancies or mistranslations.

8.1.4 Procedures

Design

A pre- and post- test design was used to determine the effectiveness of the BST programme to improve the implementation of EBPs in natural settings. A flowchart of the procedures is displayed in Figure 8.1.

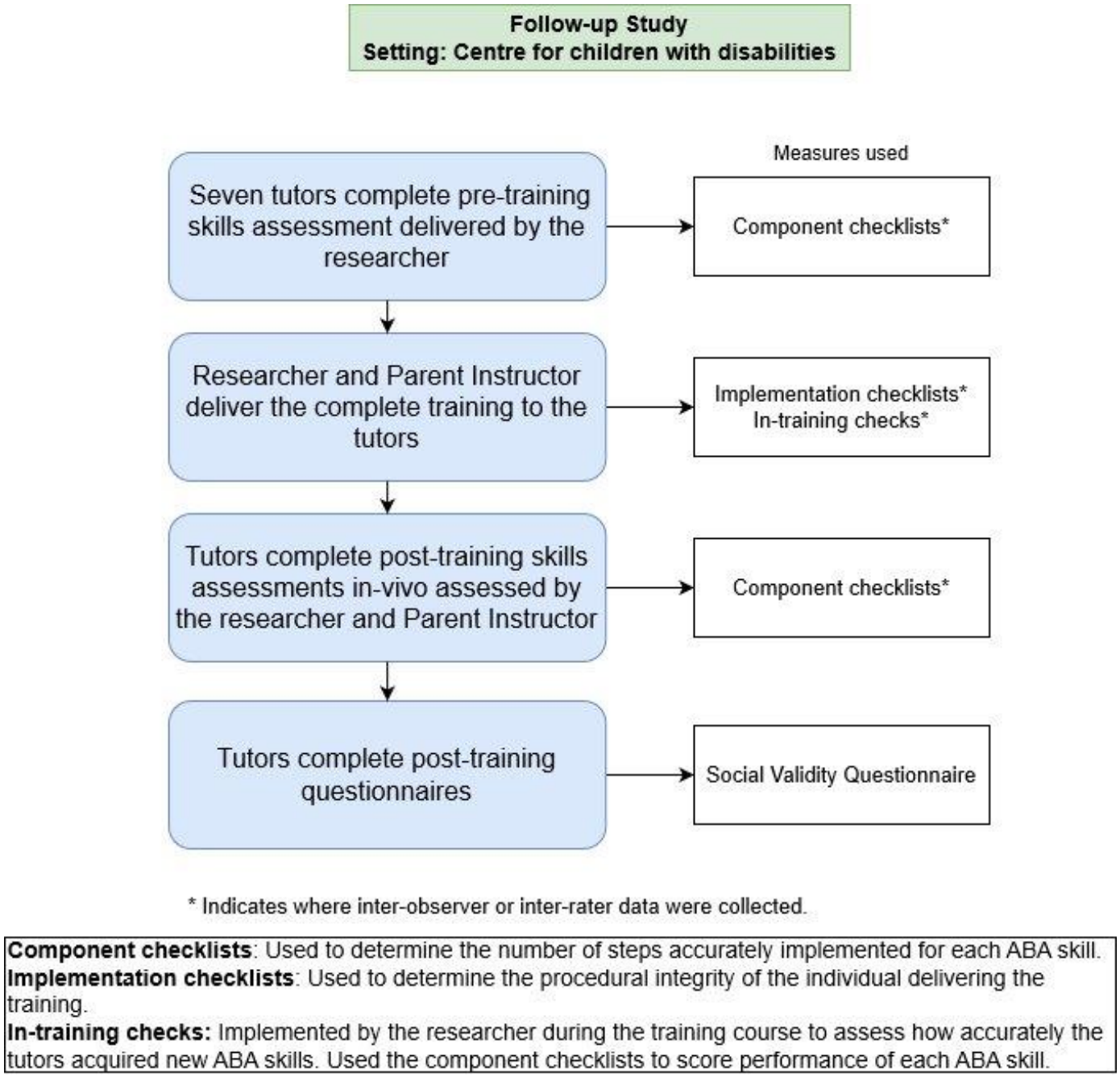


Figure 8.1. Procedures for Follow-up study.

Pre-Training Skills Assessment

The main dependent variable was performance on the *skill assessments* pre- and post-training. During the pre-training assessment, skills were performed in role play scenarios. For each skill the researcher gave the participant a copy of the component checklist. The researcher then read a scenario to the tutor and asked her to implement the skill to the best of their ability. The researcher acted as the child and responded to the tutors' instructions in a way that allowed them to practice each component of the skill. For example, while assessing discrete trial teaching, the researcher answered some questions correctly to allow for the tutor to provide a praise statement, while also answering some questions incorrectly to give the tutor the opportunity to perform error correction procedures. If they were unaware of the skill, they were instructed to say 'pass' and were given a score of '0'. Performance was scored using the component checklists. The researcher marked a '+' if a step of the skill was implemented accurately, and a '-' if it was implemented incorrectly. The number of correct steps on the component checklist implemented was divided by the total number of steps. The number was then multiplied by 100 to yield a percentage score of steps performed correctly.

Training

The training was delivered over a two-day period at the clinic. The training followed the same procedures used in Chapter 7. The tutors completed the pre-training readings as part of the first portion of the *instruction* of BST. The Parent Instructor and researcher delivered the second part of the *instruction* using PowerPoint presentations while seated around a large table. Then, the Parent Instructor or researcher performed a demonstration of the skill and/or played a video, serving as the *model.* The tutors then *rehearsed* each skill in role-play scenarios. In pairs, the tutors took turns acting as the child while the other tutor implemented each skill. During the rehearsal, the tutors often gave feedback to one another, though they were not required told to do so. This feedback was given in a positive manner and helped the

tutors correct their own mistakes and learn the skills quickly. The tutors then indicated to the researcher when they were ready for the *in-training checks*. During the *in-training checks*, the researcher observed the role play and scored each participant using the component checklist. If the tutor made an error, the researched gave them corrective feedback. *Rehearsal* and *feedback* continued until the skill was performed with 100% accuracy. After each tutor scored 100% for the skill, the next session began, and this process repeated itself for all subsequent sessions.

Post-training assessments

Post-training testing was performed in-situ during the following week at the centre during the children's usual lesson times. The researcher observed and scored the tutors implementing the skills with children they typically worked with. Tutor and child pairings are described in Table 8.1 along with a description of the task or learner outcome for each session. For example, Tutor 1 performed a functional behaviour assessment to determine the function of 'hair pulling' for the child who was pulling other children's hair during the session. The tutor later used forwards chaining to teach the child to complete a simple drawing which they have been working on for several weeks. The researcher encouraged the tutors to consider the child's cognitive, motor, and language skills and available materials when determining the child targets.

As much as possible, each skill was assessed during a typical lesson or routine to determine the efficacy of embedding the skills within a typical session. Each tutor was assessed post-training with a child for 5-8 skills and each skill was assessed with at least two tutors. The skills assessed for each tutor were based upon naturally occurring opportunities to utilize the skill with a child they typically work with. Some skills were not assessed for individual tutors due to a lack of opportunity to implement the skill. For example, if a tutor did not work with any children with challenging behaviour, the tutor would not have had the

opportunity to implement a functional behaviour assessment and was, therefore, not assessed in-vivo for that skill.

Table 8.1

Tutor and Child Pairings and Skills Assessed

Tutor	Child characteristics	ABA Skills assessment
Tutor 1	6-year-old Male	Preference assessment; used to determine the child's preferred items Functional behaviour assessment; used to determine the function of hair pulling Discrete trial teaching; used to teach completing a puzzle Error correction; for errors made while completing the puzzle Forward chaining; used to teach simple drawing technique Differential reinforcement; used for improved performance on the picture exchange communication system
Tutor 2	6-year-old Female	Preference assessment; used to determine the child's preferred toys Discrete trial teaching; used to teach receptive and expression identification (labelling) of objects and pictures of nouns Error correction; used for mistakes on the discrete trial teaching lesson Backwards chaining; used to teach simple drawing technique
Tutor 3	4-year-old Male	Preference assessment; used to determine the child' preferred toys Functional behaviour assessment; used to determine the function of screaming Prompt fading; used to teach drawing a triangle Discrete trial teaching; used for each expressive identification of items in a storybook Forward chaining; used to teaching drawing a smiley face Backwards chaining; used to teach drawing a square Differential reinforcement; used to reach multi-step imitation sequences
Tutor 4	6-year-old Male	Prompt fading; used to teach writing of first name Discrete trial teaching; used to teach gross motor imitation Error correction; used for mistakes made during discrete trial teaching Token economy; used to teaching writing skills
	10-year-old Male	Preference assessment; used to determine preferred toys and food Backwards chaining; used when teaching the application of token economy while completing a puzzle

Tutor 5	5-year-old Female	Preference assessment; used to determine preferred toys Discrete trial teaching; used to teach expressive identification of common nouns Error correction; used for expressive identification tasks in discrete trial teaching lessons Task analysis; created to teach drawing simple shapes Forwards chaining; used to teach drawing simple shapes Backwards chaining; used to teach independent use of token economy Differential reinforcement; used for increased performance of picture exchange communication system Token economy; used during discrete trial teaching lessons
Tutor 6	6-year-old Female	Preference assessment; used to determine preferred toys Discrete trial teaching; used to teach matching identical pictures Token economy; used to teach matching identical pictures
Tutor 7	9-year-old male	Preference assessment; used to determine preferred toys and food Discrete trial teaching; used to teach matching blocks to a pattern Error correction; used for mistakes made during receptive identification of pictures of animals Token economy; used to help teach receptive identification of flashcards of common nouns

Inter-observer Agreement and Procedural Integrity

IOA was collected during a random selection of 30% of pre-training assessment sessions. These assessment sessions were videotaped and assessed by a second independent researcher. IOA was collected for 100% of *in-training checks* by the researcher and the Parent Instructor. IOA was collected for 28% of the post-training assessments by the researcher and Parent Instructor. IOA was 97% for pre-test assessments, 97% for *in-training checks*, and 98% for post-training assessments following programme completion. Implementation checklists were completed after each session by both the researcher and the Parent Instructor to assess procedural integrity and was reported as 100% adherence to the programme manual for all training sessions.

Social Validity

Social validity surveys were completed by the tutors. The surveys consisted of three components: seven open-ended questions, five-point Likert scale questions, and an ABA skill rating form. The opened ended questions were categorized into four groups: overall satisfaction with the programme, perceived changes following training, perceived understanding and feasibility of the programme, and suggestions for modifications to the programme. The close-ended questions related to three categories: overall usefulness of the training components, perceived ease and appropriateness of the training, and likelihood of recommending the training to others. The ABA rating form listed 10 skills that the tutors could rate as either ‘useful’ or ‘not useful’.

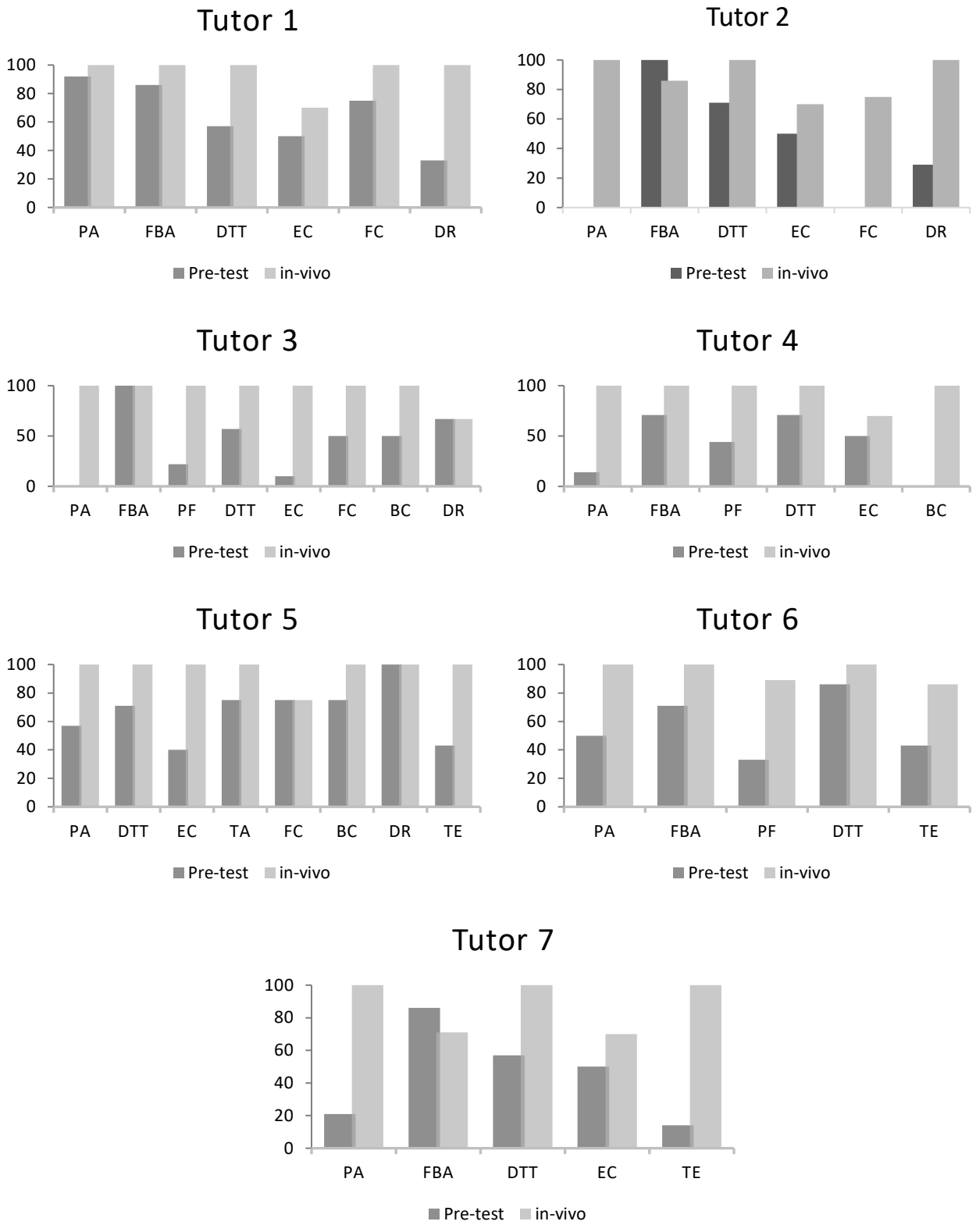
8.2 Results

8.2.1 Pre- and Post-Training Skills Assessments

Individual results for pre- and post-test scores can be found in Figure 8.1. Average pre- and post-training test scores for each skill can be found in Table 8.2. Average post-training scores include only the tutors who were tested for those skills. Each tutor was

assessed in-vivo for 5-8 skills (M=6.14, SD = 0.98) and each skill was assessed in-vivo with two-seven tutors (*M* = 4.50, *SD* = 1.74).

The average scores for each skill pre- and post-training are as follows: preference assessment 33% and 100%, functional behaviour assessment 83% and 92%, prompt fading 41% and 96%, discrete trial teaching 67% and 100%, error correction 48% and 85%, task analysis 41% and 100%, forwards chaining 32% and 83%, backwards chaining 28% and 100, differential reinforcement 57% and 89%, and token economy 35% and 93%.



Note: PA, preference assessment*; DTT*, discrete trial teaching; *FBA*, functional behaviour assessment, *PF*, prompt fading, *TE*, token economy, *FC*, forwards chaining, *BC*, backwards chaining, *DR*, differential reinforcement, *TA*, task analysis.

Figure 8.1. Tutor pre- and post-training skills assessment scores.

Table 8.2

Average Skill Scores When Assessed in Role-Play Scenarios Pre-Training and In-Vivo Post-Training

	Preference assessment	FBA*	Prompt fading	Discrete trial teaching	Error correction	Task analysis	Forward chaining	Backward chaining	DR*	Token economy
Pre-training	33.4	83.6	41.0	67.1	48.6	41.1	32.1	28.6	57.0	34.9
Post-training	100	92.8	96.3	100	85	100	83.3	100	89	93

**Note: FBA,* functional behaviour assessment; *DR,* differential reinforcement.

8.2.2 Social Validity

A five-point Likert scale was used to rate the overall usefulness of the programme, understanding and feasibility of the training, and the likelihood of recommending the programme to others. Results from the surveys are displayed in Figure 8.2. Tutors found all aspects of the training useful, with the role-play/ practice sessions to be the most useful (5/5), followed closely by the video models (4.8/5), and the supporting PowerPoint presentations (4.1/5). Tutors were neutral in their ratings of the ease of learning ABA content (3.5/5) and the ease of using the skills with the children (3.1/5). However, the tutors rated ABA very highly for its appropriateness for use with children with autism (4.8/5). Most tutors felt confident in their ability to use the strategies with the children (4.3/5) and were likely to recommend the training course to someone else (4.4/5).

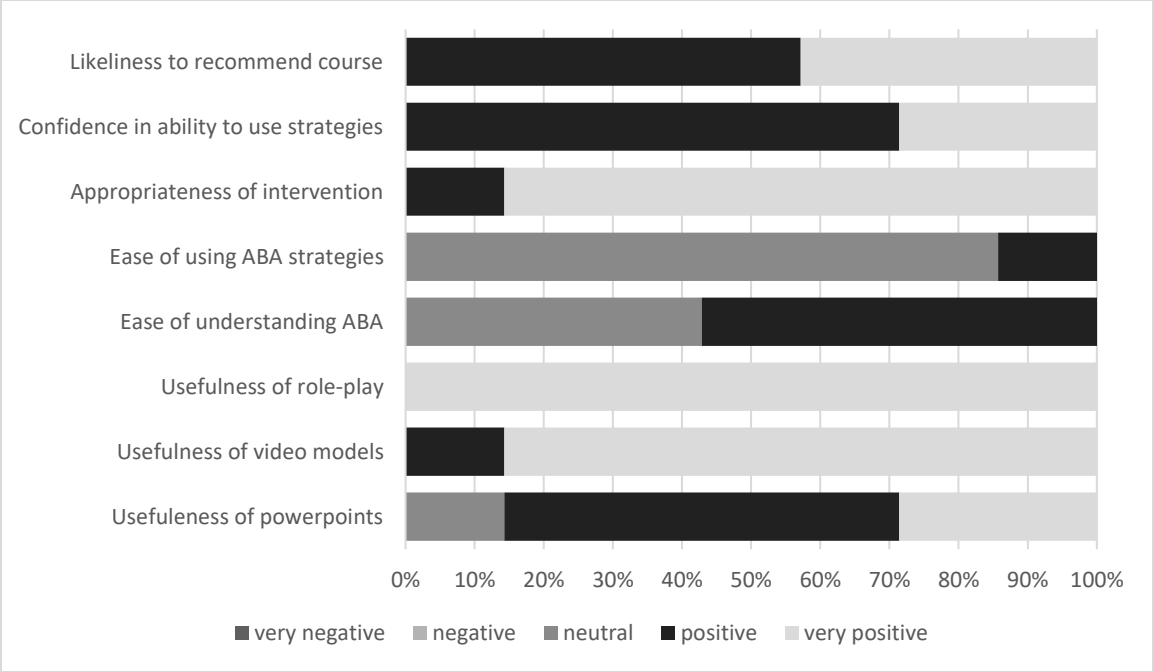


Figure 8.2. Tutor responses to social validity questionnaires.

ABA rating form

Overall, the tutors rated the usefulness of the ABA strategies very high. All tutors scored every skill as useful, except for continuous measurement, differential reinforcement, and 'wait'. However, these skills still rated highly with 86% of tutors rating continuous measurement and 'wait' as useful and 75% of tutors rating differential reinforcement as useful.

Open-ended questions

The responses to the opened ended questions were similar across the tutors; All tutors reported that the practice opportunities (*rehearsal*) were the most useful aspect of the training. None of the tutors identified any aspect of the training as unhelpful. All tutors reported that it was 'easy' to understand the basic concepts of ABA. When asked about the easy of using the skills with the students, the tutors stated that it was useful that they had prior experience implementing ABA. They did state, however, that they ran into difficulties tailoring the skills to the individual children.

The tutors noted changes in their teaching: 'We have refreshed our ABA knowledge we had previously learned and gained new skills'. One tutor stated, 'I have now started using reinforcement. I realize now why the children ignore me and have begun implementing a token economy.' Additionally, the tutors commented on the changes in their interest in ABA. All but one tutor indicated that their interest in ABA increased: 'Now I can see the benefits of ABA strategies.' Five of the seven tutors indicated that they have noticed positive changes in the children since the training: 'The children have become more motivated', 'The children work harder and are faster in following directions.' One tutor stated that she has not yet noticed any changes, while another tutor did not comment.

The tutors suggested that the researcher ‘make the training longer’ and include sections on ‘how to create individualized ABA programmes.’ In the final opened ended question, six tutors responded. The comments were positive, but all indicated the desire for local trainers and ongoing support:

> “I would like to meet more often for more training and practice. During the ABA lessons with autistic kids, we face many problems and it will be difficult to solve all of the problems.”
>
> “This study was a wonderful experience for me, but my knowledge is not complete, and I don’t have quite enough practice. It would be great to have an ABA supervisor here in Kazakhstan.”
>
> “I want a ABA supervisor here because more questions will arise as we work with the children.”
>
> “I would love if we had an ABA expert in our country- we currently have no such experts.”
>
> “We need an ABA expert here to help us continue to use ABA.”
>
> “We need more time for questions and answers, because it is difficult to ask questions when we are working with the children.”

8.3 Discussion

The current study builds on the research performed in Chapter 7 on the effectiveness of a manualized group BST programme that assessed skills in role-play scenarios only. This study assessed the extent to which the skills taught in role play scenarios would translate to use while working with a range of children with autism and developmental disabilities. For all but one skill for one participant, the results suggest that the skills learned in role-play training can be accurately applied to working with children on a variety of tasks. Tutors were able to utilize the skills with children with a high level of fidelity. The skills were used to teach more than eight children at various ages and ability levels. Tutors were not given any additional training or

support on how to implement the skills within their ongoing lessons with the children. The tutors demonstrated an ability to independently apply the skills learned and incorporate them into their existing lessons.

The tutors rated the training programme very highly in the social validity survey. There were no negative responses to the closed-ended or open-ended questions. The tutors reported finding the training very useful and appropriate for their setting. They did, however, comment on the desire for ongoing support. They also requested further training on how to respond when children make errors or exhibit challenging behaviours during the lessons. They also requested further training on how to create 'ABA treatment programmes', as there are no specialists onsite to create the plans and they were unsure of how to organize their learner's lessons moving forward. Ongoing supervision and support from a BCBA (whether in-person or telehealth) would be needed to design and monitor ongoing ABA treatment plans. Despite these limitations, the tutors were very satisfied with the training and noted perceived improvements in the children's performance as a result of the training.

These findings are to be considered with caution. While the tutors were able to implement the skills with accurate scores on the checklists, they did not always implement the skills analytically. For example, when Tutor 5 was tested for DTT, she held up different coloured and shaped blocks. She asked the student, "What colour?" and the student would respond with the colour. She then held up four different blocks and repeated the instruction for each block. On the sixth trial she asked, "What shape?" and the student responded with the block's colour. She accurately implemented error correction procedure and continued to ask the student the block's shape for four more trials. She then switched and asked the student "What's the colour?" and the student responded with the shape. An experienced behaviour analyst would likely be able to

quickly determine that the child was not attending to the question when providing an answer and instead use their previously reinforced answer as the basis for their next response. However, the tutor was not able to identify this pattern. Since the tutors was not able to recognize this types pattern, they were likely to persist using unhelpful strategy for the remainder of the session.

Error correction was one of the lowest scoring skills during the post-training assessments, although the average score was high (85%). However, many of the tutors failed to generalize this skill. When told they would be assessed for their error correction implementation during the child's next mistake, they implemented error correction with high levels of accuracy. Outside of the testing session however, the tutors did not implement the error correction procedures during child mistakes. This skill was only used when specifically instructed to do so. These examples highlight the need for ongoing supervision from a highly qualified and experienced professional and the limitations of short-term initial training programmes.

These limitations should be carefully considered when planning international training programmes in locations with limited BCBAs. Without ongoing support and supervision, attendees of short-term training programmes may return to their settings and begin delivering 'ABA therapy'. However, their therapeutic work may be of low quality and result in poor outcomes. This could also negatively impact the perception of ABA as a profession. As with all intervention training programmes, the ethics of short-term training and potential for harm should be carefully considered before their delivery.

This study demonstrated that performance skills can be taught using manualized BST in a group, role-play format and those skills can transfer to working with a variety of children on a variety of skills. A manualized training programme saves planning time and promotes consistent, systematic training. Combined with ongoing supervision, this programme provides a time and

cost-efficient system for providing training in low-resource areas. Future research should be performed to assess maintenance of skills and the required level of ongoing supervision or 'booster' training session to keep implementation scores high. Additionally, more research should be performed to determine child outcomes when their tutor has been trained with BST versus other forms of training (didactic, online, etc.).

9. General Discussion

9.1 Thesis overview

This thesis provided a thorough account of the experiences of individuals with autism and their families in Eastern Kazakhstan. Evidence from Chapters 3, 4, and 5 provide historical and present-day descriptions of the difficulties autistic individuals face in Eastern Kazakhstan. In response to these difficulties, a novel manualized training programme created for the purpose of providing high-quality training to individuals in low-resource areas and is described in Chapter 6. The main study in Chapter 7 utilized the training manuals in a pyramidal training approach to train mothers of children with autism to deliver the training to university students. The pyramidal training structure was successful in preparing the mothers to deliver the training with a high degree of fidelity. The university students were able to quickly learn to implement all ABA-strategies in the training. A follow-up study determined that skills learned through the training programme successfully generalized to use with children with autism and related disabilities.

9.2 Research aims and questions

This thesis sought to achieve four research aims and investigate five research questions related to one of the aims. The research aims first were listed in section 1.1 and were subsequently identified as they were addressed in the chapters throughout this thesis. A discussion of the findings for the research aims and questions is presented in the sections below.

9.2.1 Aim 1:

Perform semi-structured interviews with mothers of children with autism in rural cities to gain insights into their perspectives on obtaining a diagnosis, finding an educational placement, and experiences stigma in the community. Explore the ways in which their

experiences are the same or different compared to families who live in the two major cities, Almaty and Nur-Sultan.

This qualitative study was the first to explore mother's experiences of autism outside of the major cities in Kazakhstan and was the first in the country to performed in-depth interviews. Three themes were identified in this study: a) difficulties obtaining a diagnosis and receiving an assessment, b) inappropriate and insufficient education and provisions, and c) dedication to working towards a better future. This study brought to light the hardships and difficulties the families face while navigating through the disability policy and procedures in Kazakhstan. Many of the mothers described the emotional strain and financial burden of having a child with autism. Additionally, they described their struggle to obtain suitable services for their child. The results from this chapter indicates the need to closely examine and evaluate the current diagnostic procedures. It also provides evidence for the need for the creation of new training programmes and more highly qualified professionals to work with autistic children.

9.2.2 Aim 2:

Produce a reflective report, based on personal experiences in Kazakhstan, to provide context and discuss the current diagnostic process, professional training, and private services available in Eastern Kazakhstan.

The purpose of this aim was to provide a context for the subsequent studies in thesis, as well as share the experiences and reflections from the field visits. By drawing upon methods from focused ethnographic research, multiple sources of data were presented to provide a description of the topics identified in the aim. This report includes an account for a site visit to the psychiatric hospital where the children attend to receive a disability diagnosis. To the best of our knowledge (the research and director of the local centre) this was the first time an individual

was allowed to tour the entire facility. The information gathered from this opportunity is shared in the report and provides further insights into the diagnostic process than was able to be obtained from the mothers in Chapter 3. While this chapter is not a rigorous, scientific study, it was successful in present novel information that is useful to a wide range of individuals who may be interested in autism in Kazakhstan.

9.2.3 Aim 3:

Develop a training manual, based on current best practices and sensitive to the cultural context of Kazakhstan, to train parents and university students to work with children with autism in schools using a train-the-trainer model approach.

Aim 3 was identified out of necessity for an appropriate training manual for this project. Existing training materials were mostly in English and were not designed to facilitate BST. Most available training materials were written instructions or training videos that were didactic in nature and did not plan for rehearsal and feedback of performance skills. Therefore, an appropriate training manual was created for this project. The training manuals took several months to plan, create, and revise. Published training manuals for related interventions (cognitive behavioural therapy, anxiety, parenting, etc) were used as models for format and design. During the revision period, additional sections were added, such as 'dealing with difficulties', to provide additional support and information for those individuals using the manuals following the research studies.

Obstacles were encountered during the translation, printing, and binding of the manuals. The manuals were first written and formatted in English before being translated into Russian. Several translators worked on the project, with different translators completing various chapters. Some translators took care to ensure that the formatting of the manuals remained the same after

translation, whereas others did not. This led to some figures or graphs to be split between pages or awkwardly laid out. This impacted the overall usability of the training materials and required additional, last minute editing to resolve the formatting issues.

There were additional difficulties with the translation of ABA terminology. An official list from the Behaviour Analyst Certification Board of Russian translated ABA terms was obtained, however, this list was not satisfactory to many of the translators. The translators noted that several of the terms were 'oddly' translated and did not make sense. When the official list of ABA terminology was obtained from the BACB, the Director of International Development revealed that the list was created by a group of Russian behavior analysts and other scientists. He stated that the group very carefully researched each term and reflected upon the origins of certain terms (e.g. how Skinner or Pavlov first used them) to come up with the most literal Russian translation. While the terms may have been very precise translations, the translators and mothers argued that they were not practical or clear. Many wanted to make changes to the translation list to improve clarity. However, the official list was used for in the training since those are the terms the BACB had agreed upon for the final translation. The reasoning for this decision was to promote consistency; should one of the participants take am exam for BACB certification in the future, it was thought that it would be confusing to use multiple different terms for the same concept.

9.2.4 Aim 4:

Assess and evaluate the feasibility, acceptability, and efficacy of the training programme.

This aim was identified to assess the overall success of the training program implemented in the main study and follow up study in this thesis. The two studies allowed for this aim to be measured in two separate settings with different participant groups. Central to this aim was not

solely whether the training course was effective, but whether or not it was effective in the context of rural Kazakhstan. In this geographic location stigma, discrimination, and lack of awareness was a pervasive issue (Markova & Sultanalieva, 2013). Most of the professionals had been trained in a very different approach to working with disabled populations. Very few ABA training courses had been available in the entire country, with almost none in Eastern Kazakhstan. With the lack of BCBA's and resources to pay for international consultants, it was necessary to evaluate the efficacy of a stand-alone training course delivered by local individuals without the support of others. Thus, the scripted manuals were created and the mothers were trained to deliver the training without the assistance of the researcher. In order to fully evaluate this aim, four research questions were identified:

9.2.5 Research Question 1:

Can this course teach parents, students, and professionals to accurately implement ABA strategies?

This research question was addressed in both the main and follow-up study. In Phase 1 of the main study the Parent Instructors displayed the ability to quickly implement the ABA strategies accurately, with most Parent Instructors implementing the skill with 100% accuracy on the first or second attempt. The Parent Instructors were then able to accurately deliver the training and model the skills learned with a high degree of fidelity. Throughout the training and rehearsal, the implementation of the token economy proved to be difficult for the Parent Instructors to master. This skill took the longest to master during the initial training and had the lowest fidelity score during the rehearsal and Phase 1 implementation. This skill was complex and required the mothers to use skills acquired in previous sessions (prompting, prompt fading, and reinforcement), which may have contributed to the lower scores.

The university students in Phase 2 scored low across all skills during the pre-training assessment. After the training, all university student scores increased significantly. Similarly, during the follow up study the tutors demonstrated immediate improvements across skills. Tutor and university student pre- and post-training scores are compared in Table 9.1. This is not a true comparison, as the tutor's post-training assessments were performed in-vivo with children and the university students' scores were assessed in role-play scenarios. Nevertheless, the comparison demonstrates interesting results. The tutors began the course with a higher level of skills than the university student pre-training. These skills were acquired during their two-week pre-employment training course at the centre. Post-training, the tutors performed with a higher degree of accuracy than university students on all skills, except for forwards chaining (see Figure 9.1). During the tutor training in the follow-up study, the tutors revealed that they local psychologist who delivered their pre-employment training provided them instructions for delivering forwards chaining. The reported that she did not train them in backwards chaining, and instead instructed them to always use forwards chaining. The psychologist's implementation of forwards chaining varied slightly from the implementation used in the study. It is possible that the tutors struggled to perform this skill accurately as the had previous training in a different approach and had a difficult time adjusting their practice. This may explain why forwards chaining was their lowest scoring skill and the only skill they performed worse on than the university students. Overall, the tutors higher post-training score may have influenced by their higher pre-training scores, their experience working with children with autism, or their ability to apply the concepts and skills learned to their current students.

Table 9.1

Comparison of University Student and Tutor Pre-and Post-Training Skill Assessment Scores

	Preference assessment		Functional behaviour assessment		Prompt fading		Discrete trial teaching		Error correction		Task analysis		Forwards chaining		Backwards chaining		Differential reinforcement		Token economy	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Tutor	33.4	100	83.6	92.8	41.0	96.3	67.14	100	48.57	85	41.1	100	32.14	83.3	28.57	100	57.0	89	34.9	93
Student	5.9	95.6	8.0	87.2	7.3	84.2	5.4	82	5.7	69.5	1.1	81.2	2.4	93.7	0.0	82.3	6.8	77.9	3.3	86.4

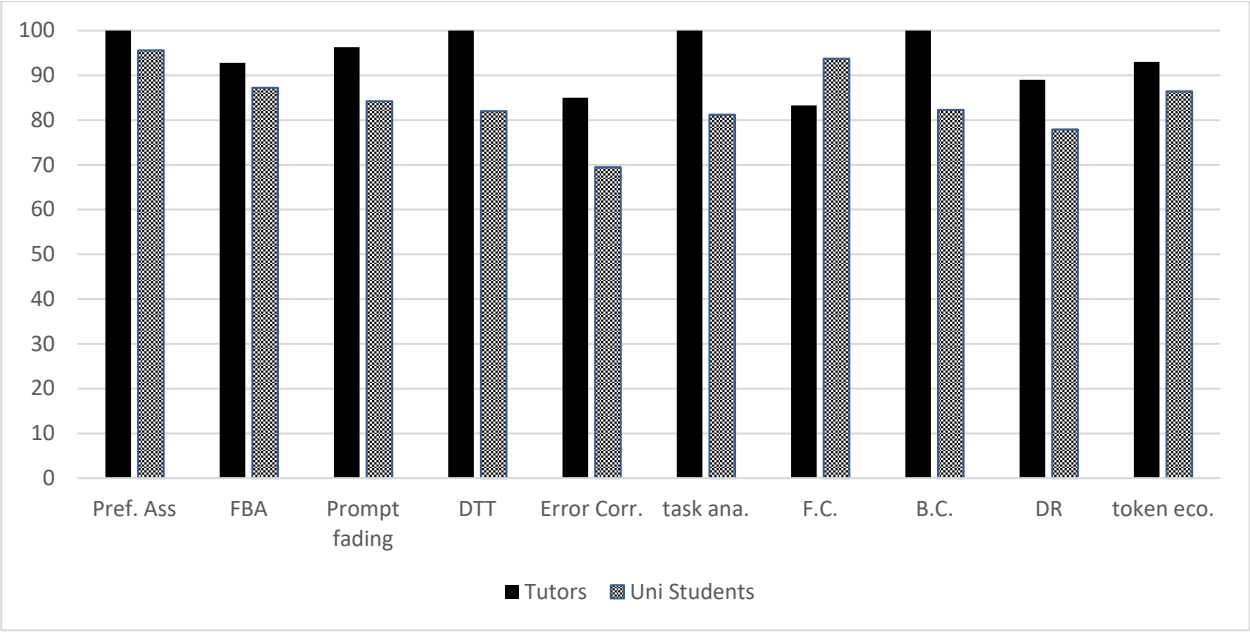


Figure 9.1. Comparison of post-training scores from university student participants in main study and tutor participants in the follow-up study.

The results from these studies support previous BST research that suggests that ABA skills can be taught quickly and that pyramidal teaching models following BST can be used to effectively train lay-people to deliver the training (see Chapter 2, Part 3 for more details; Parsons, Rollyson, & Reid, 2013).With the question addressed, an additional question to consider is, *Should manualised, BST programs be delivered by lay-persons in countries with restricted access to BCBAs?* As discussed in Section 8.3, while the tutors were able to accurately implement the skills, there were issues with their application. Additionally, both the university students and the tutors noted in the open-ended questions the desire for more information from a professional with more qualifications than the Parent Instructors. The Parent Instructors s also indicated that they were unable to answer all the university student's questions due to their limited knowledge. Thus, without support and ongoing supervision from a BCBA, short-term trainings, such as the one based on the manual developed in Chapter 6, may lead to trainees implementing poorly designed 'ABA lessons.'

This concern was discussed in Section 8.3 of this thesis and should be considered in light of the information presented in Part 2 of Chapter 2 in this thesis. Early application of therapy based on the principles of ABA utilized punishment procedures, included slaps and sprays of water (Lovaas, 1987). These punishment procedures came under heavy criticism and have since been addressed by the BACB's ethical guidelines to promote positive application of ABA. Though these aversive punishment procedures are not a part of most contemporary ABA practices, the field is still under scrutiny, particularly on social media. Given the intensity of the debate, and the high stakes of working with vulnerable populations, the training of professionals should be carefully considered. Poorly qualified professionals may provide low-quality services, which may in turn result in unfavorable outcomes. This may, at best, perpetuate thoughts that interventions based on the principles of ABA are not appropriate for children and adults with autism, or at worst could lead to potentially dangerous interventions.

9.2.6 Research Question 2:

Is this training course feasible and acceptable to parents, students, and professionals?

Results from phase one of the main study indicate that the mothers were able to learn the various ABA skills very quickly. The rehearsal probes suggest that they were able to accurately deliver the training, needing only minor coaching. During the Phase 2 training of the university students, procedural integrity was high, demonstrating that the Parent Instructors were able to independently deliver the training with a high degree of fidelity. The results suggest that a pyramidal training approach is an effective model for training non-experts to deliver the manualised training programme.

Social validity scores across both the Main Study and Follow-Up study were predominately positive, suggesting that this training is acceptable in the cultural context of Kazakhstan. On five-point Likert scale questions, with 1 being 'very negative' and 5 being 'very positive', no scores below '3' (neutral) were reported by the parents, university students, or tutors. Very few negative comments were made in open-ended questions. Most participants were satisfied with the training and would recommend the course to other. One comment that reoccurred throughout the social validity questionnaires was the desire for on-going training and support from local staff. These comments, once again, highlight the importance of thoughtfully delivering short-term trainings in low-resource areas and the need for developing highly skilled local professionals.

9.2.7 Research Question 3:

Can this course increase students and parents' knowledge of autism and ABA?

The training course was effective in increasing all participant's knowledge of autism and ABA. Overall post-training scores were high for the university students. There were three sessions that scored substantially lower than others. For each of those sections there were one or two questions that scored extremely low. The reasoning behind these low scores remains unclear. These low answers may be due to the questions being poorly translated or may be attributed to the mothers incorrectly explaining the topic. The translation of these questions should be reviewed prior to the future use of the exams for subsequent training or research purposes. Had the low-scoring questions

been removed, those session would have scored similarly to the other sessions, suggesting that this training programme was effective for teaching knowledge across all content areas.

The knowledge exams were not given to the tutors, but it is suspected based on their high performance skills scores that their knowledge also increased. The knowledge exams were not given to the university students' due to a lack of time and resources; the last-minute schedule change to the Main Study resulted in changes in printing and other logistical aspects (arranging for the projector, communicating with all participants and translators, etc.). Had the ABA and Autism Knowledge Exams been completed by the tutors, a comparison could have been made between them and the university students. This would have allowed for an analysis of pre-training knowledge and skill performance.

9.2.8 Research Question 4:

Can this course change student attitudes towards inclusive education and autism?

This training programme was not successful in improving university students' attitudes towards inclusive education or autism. This may be due to the brevity of the training; results may have improved had the course been longer or if the university students were given an opportunity to interact with individuals with autism and test their new skills. Score may also be influenced by the lack of resources available within the schools to support students with special needs. Individual items such as, "*I am concerned that students with disabilities will not be accepted by the rest of the class*" did not results in significant changes. This is unsurprising, as this course did not have an impact on the attitude of other students that would be in the classroom, nor did it prepare the university students to explain or help the classroom students better interact with children with autism.

9.2.9 Research Question 5:

Can this course increase parental empowerment?

The results from the main study suggest that the training manuals, in combination with the pyramidal training approach, were successful in improving the Parent Instructor's sense of

empowerment. The Parent Instructors reporting enjoying participating in the course and appeared to take their roles seriously. Overall, scores of the FES improved. The subdomains of Family and Community improved, however, Service Systems did not. Service systems is defined as the parent's ability to work with professionals and access services their child needs. This may not have been significant due to there being extremely limited services for the mothers to access, which did not change from before to after the training.

This study did not assess any negative impacts of participating in the study. Participation required a substantial time commitment that necessitated the Parent Instructors to arrange for childcare. This was difficult for many of the Parent Instructors who do not have many childcare options. Additionally, all Parent Instructors had to arrange transportation, which was difficult for some who did not have cars. However, these obstacles did not prohibit the mothers from scoring significantly high on the FES post-training. Anecdotally, the Parent Instructors commented at the end of the project that they felt it brought them closer together.

9.3 Implications

9.3.1 Implications for clinical training

The results from the main and follow-up study suggest that non-experts can quickly become trained to deliver a manualized BST to other non-professionals. School, clinics, and other organizations can incorporate the results from these studies into their onboarding and ongoing staff training efforts. Using a pyramidal training approach, highly qualified BCBA's at their respective institution can train a small group of non-experts to deliver the training to the bulk of the staff. This would lessen the training burden on the BCBA while still delivering high-quality training to new staff. The BCBA should, however, be available to answer difficult questions that the novice trainers are unable to answer. Additionally, results from the follow-up study suggest that after the initial training, it is beneficial for feedback sessions to occur with the BCBA to ensure that the ABA skills are being implemented in the manner intended. Finally, feedback from the tutors suggested that more information on how to respond when the children make incorrect or unpredictable responses

be added. It would be advantageous for training programmes to include practice sessions and feedback specifically for dealing with difficult situations.

9.3.3 Implications for policy

Results from Chapters 4 and 5 of this thesis uncovered information detailing the difficulties families face attempting to obtain a diagnosis and receive treatment. The findings from these chapters may be useful when address these policies and procedures and updating them to international standards. The studies performed in the main and follow-up chapters are the first to demonstrate that well-designed training packages are feasible, acceptable, and effective in the cultural-context of Kazakhstan. The parents and professionals in the Eastern region of the country were able to quickly learn and accurately implement the strategies. This provides evidence support the future training and development of graduate level courses in behavior analysis. The findings can be used in future advocacy efforts to further develop and progress the situation for individual with autism and their families.

9.4 Limitations and Future Research

The findings in this thesis should be interpreted with a number of considerations. There is limited historical and present-day information about disability and autism in Kazakhstan, and even less so in English. There may be more detailed information in Russian which was unable to be included into the literature review chapters. Additionally, certain aspects of Kazakh culture, history, and society may have been misinterpreted due to the researcher having a different cultural background. The language barrier also could have impacted both informal and formal conversations.

An additional difficulty across all chapters which included participants was the credibility of the child's diagnosis. Given the lack of standardized assessment tools, it is not certain that every child who had a diagnosis of autism truly had autism and it is likely that there were several children who did have autism that had not yet obtained a diagnosis. Regardless of this discrepancy, all

mothers of children with various developmental disorders in this thesis share similar stories, struggles, and achievements. As the diagnostic process improves in Kazakhstan, future studies can investigate the subtle difference and challenges that mothers of children with autism versus other disabilities face.

A final consideration of the main and follow-up studies is that there is no child outcome data. While the trainees in both studies quickly obtained skills, it is unclear whether or not the children they work with will have improved performance relative to children whose instructors have been trained with a different programme. Future research should investigate the extent to which children benefit from instructors trained with behavioural skills training differ to those who were trained with didactic or self-paced instruction. Additional studies should also investigation the long-term maintenance of the skills learned during initial behavioural skills training programmes to better determine the frequency of follow-up supervisions to maintain a high level of accuracy.

9.5 Autobiographical Reflections

As an American researcher, competing the research projects within this thesis was an eye-opening experience. Though I have spent substantial amounts of time living, working, studying, and traveling around the world, the primary lenses with which I view the world still belongs to native culture. Having worked in the ABA field professionals for several years in the USA, where ABA is widely acceptable and available, moving to UK was very jarring. I found myself in a constant defensive state where I was spending more time defending the field of ABA than talk about my actual research. This was not entirely unhelpful, as this situation required me to critically analyse the current state of ABA practice and research and not simply accept the status quo. Despite the professional growth, this still remained a difficult sticking point during my time in the UK

These experiences, however, were quickly put into perspective during the field visits to Kazakhstan. Whereas in the USA the major battle most providers and families face is with the insurance companies and in the UK the conflict is between professionals and autistic adults, in Kazakhstan the families are still struggling just to be seen and heard. Parents are afraid to show

their children in public, the government is ignoring the problem, and adequate diagnostic and treatment provisions are non-existent. This experience helped clarify for me, both professionally and personally, the difference between real problems and minor ones. Certainly, in the USA having an insurance provider require you to complete assessment A after you completed assessment B before they will authorize you to begin services is an inconvenience, but is a problem that can be remedied by spending an extra hour or two assessing the individual to obtain services. In the UK the debate continues on whether to use person-first or identify first language. Of course, language matters and the way in which we think about and talk about disabilities is important as everyone has a right to dignity and respect. However, could the amount of time and energy currently targeted toward that issue be better spent addressing the significant issues many families are facing around the world? One would hope, that differences could be put aside and various parties could come together to work toward the shared goal of greater acceptance, awareness, and support.

My time in Kazakhstan proved to be equally rewarding and saddening. As a researcher, it was exciting to see my studies take place and obtain positive results. As a clinician, it was enjoyable to train parents and professionals to learn new skills they otherwise would not have learned. As a person, it was a honour to be welcomed into the lives of the families and be a small part of their journey. Despite these successes, it was difficult to see the families struggle. It was frustrating to see a child, who with intensive interventions would likely blossom and develop skills quickly, stagnate and not progress. It was extremely difficult to look a parent in the eye and tell them that I could not help their child, given the small amount of time I was there, knowing that if their child lived in the US I would be able to help them. When the direness of the situation pulls me down, I look to the parents, who despite all odds have improved the situation for their children, as a source of inspiration and motivation for future advocacy and work.

9.6 Conclusion

The research aims established in the first chapter of this thesis were addressed throughout the subsequent chapters and studies. Chapters 3, 4, and 5 describe the issues facing autistic

individuals and their families and provides a foundation for the need for high quality training initiatives. The novel training programme developed for the main and follow-up study was successful in teaching ABA skills and knowledge. This manualized training programme directly addressed the lack of qualified professionals and training opportunities in Eastern Kazakhstan. This thesis provides a unique solution to one of the current barriers to accessing treatment. This training programme, combined with ongoing parent advocacy and the development of high-quality graduate programmes will help to update, improve, and make autism services more widely available in Kazakhstan.

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11. Appendices

Appendix A. Detailed description of quality indicators.

Table A

Definition of Quality Indicators Unchanged from Reichow (2008)

Quality indicator	Definition
Primary quality indicator	
Participant characteristics	Age and gender were provided for all participants, specific diagnostic information was provided for all participants with autism, if applicable, standardized test scores were provided, and information on the characteristics of the interventionist was provided
Independent variable	Information about the treatment was provided with replicable precision (if a manual was used, this was always given a high quality rating)
Dependent variable	Dependent measures were described with operational and replicable precision, showed a clear link to the treatment outcome, and were collected at appropriate times
Baseline condition	All baselines (a) encompassed at least three measurement points, (b) appeared through visual analysis to be stable, (c) had no trend or a counter therapeutic trend, and (d) were operationally defined with replicable precision
Visual analysis	All relevant data for each participant was graphed. Inspection of the graphs revealed (a) all data appeared to be stable (level and/or trend), (b) contained less than 25% overlap of data points between adjacent conditions, unless behavior was at ceiling or floor levels in previous condition, and (c) showed a large shift in level or trend between adjacent conditions which coincided with the implementation or removal of the IV (note, if there was a delay in change at the manipulation of the IV, the delay was similar across different conditions and/or participants [±50% of delay])
Experimental control	There were (a) at least three demonstrations of the experimental effect, (b) at three different points in time, and (c) changes in the DVs covaried with the manipulation of the IV in all instances of replication (note, if there was a delay in change at the manipulation of the IV, the delay was similar across different conditions or participants [±50% of delay]).
Secondary quality indicator	
Interobserver agreement	IOA was collected on at least 20% of sessions across all conditions, raters, and participants with inter-rater agreement at or above .80
Kappa	Kappa was calculated on at least 20% of sessions across all conditions, raters, and participants with a score at or greater than .60
Fidelity	Procedural fidelity and/or treatment fidelity was continuously assessed across participants, conditions, and implementers with reliability at or greater than .80
Blind raters	Raters were blind to the treatment condition of the participants

Generalization and/or maintenance	Outcome measures were collected after the conclusion of the intervention to assess generalization and/or maintenance
Social validity	The study contained at least four of the following; (a) DVs were socially important (i.e., would society value the changes in outcome of the study), the (b) intervention was time and cost effective (i.e., did the ends justify the means), (c) comparisons were made between individuals with and without disabilities, (d) the behavioral change was large enough for practical value (clinically significant), (e) the consumers were satisfied with the results, (f) people who typically come in contact with the participant manipulated the IVs, (g) the study occurred in natural context

Appendix B. Interview guide from qualitative study.

Interview Guide

Introduction:

Thank you for taking the time to be interviewed as part of my research project. The purpose of this interview is to gain insight into your experience of raising a child with autism in Kazakhstan. I would like to know your views and experiences of the diagnostic process, the committee meeting, your child's current educational provision and your general thoughts on education and autism in Ust-Kamenogorsk. Your responses will be kept anonymous. Depending on the length of responses you would like to provide, this interview will last approximately 30 minutes.

Diagnostic process and educational assessment

When was your child diagnosed with autism?

What was the diagnostic process like?

What was the school committee application process like?

Please describe the process of attending the committee meetings.

If you were denied/ were to have been denied, is there a possibility you could petition to be let in?

Is there anything else you would like to add about the diagnostic process or the committee procedure?

Current educational placement

What kind of school or rehabilitation centre does your child attend?

Describe your child's current educational provision?

- How many hours each day does your child spend at school/rehabilitation centre?
- How many days a week does your child spend at a school/rehabilitation centre?

What do you feel about the quality of teachers?

What are your views on their knowledge and formal training?

How is the communication between you and your child's teachers?

How do you feel about the security of your child's placement at school/rehabilitation centre?

What are your options if your child gets removed from their current setting?

Is there anything else you would like to add about your child's current educational provision?

Your child's future

How would high quality education change your child's life?

How would high quality education change your life?

What are your hopes for your child?

Is there anything you would like to say about your child's future or what a high-quality education would mean to you?

General comments on education for children with autism

What are your views on the availability of school for students with autism?

What are some barriers to children with autism getting an education?

What changes would have to be made in order for children with autism to have access to education?

Do you have any final comments or thoughts on education for children with autism in Kazakhstan?

Appendix C. Participant pre- and post- training questionnaires.

Parent Pre-course questionnaire
Parent ID_____

Family Information

A. What is your age? _____
B. What best describes your current employment?

- ☐ Stay at home parent
- ☐ Full time
- ☐ Part time
- ☐ Unemployed

C. What is your highest level of education?

- ☐ Some higher secondary school
- ☐ Completed secondary school
- ☐ Some university
- ☐ Bachelor degree
- ☐ Graduate or advanced degree
- ☐ Other:_____

D. What is your marital status?

- ☐Married
- ☐ Re-married
- ☐ Never married
- ☐ Divorced
- ☐ Other:_____

E. If married, what best describes your spouses' current employment? Skip if unmarried.

- ☐ Stay at home parent
- ☐ Full time
- ☐ Part time
- ☐ unemployed

F. What is your spouse's highest level of education?

- ☐ Some higher secondary school
- ☐ Completed secondary school
- ☐ Some university
- ☐ Bachelor degree
- ☐ Graduate or advanced degree
- ☐ Other:_____

G. Household income

- ☐ Low

☐ Middle

☐ High

H. What best describes your ethnicity?

☐ White…

I. What best describes your child's ethnicity?

☐

J. What is your child's date of birth? _____ (DD/MM/YR), my child is ____ years old.

K. How many siblings does your child have? _____

Educational information

L. What is your child's current educational provision?

☐ None

☐ Home tutor

☐ Rehabilitative centre

☐ Specialist School

☐ Mainstream School

M. How many hours per week is your child receiving those provisions? _____ hours a week

N. What additional therapeutic services is your child receiving? Check all that apply

☐ Speech therapy ____ hours per week

☐ Occupational Therapy____ hours per week

☐ Psychologist sessions____ hours per week

☐ Defectologist sessions____ hours per week

☐ Horse Therapy ____ hours per week

☐ Swimming Therapy____ hours per week

☐ ABA Therapy____ hours per week

☐ Son-Rise Therapy____ hours per week

☐ Holding Therapy ____ hours per week

☐ Other: _____

Medical Information

O. Childs diagnosis (check all that apply)

☐ Autism Spectrum Disorder

☐ Aspergers

☐ Pervasive Developmental Disorder Not Otherwise Specified

☐ Attention Deficit Hyperactive Disorder

☐ Apraxia

☐ Aphasia

☐ Epilepsy

☐ Obsessive Compulsive Disorder

☐ Bi-Polar Disorder

☐ Depression

☐ Anxiety

P. What was your child's age at diagnosis? _____

Q. Is your child currently on any medications?
No Yes Don't know
If yes, please state all medications: _____

R. Is your child taking any supplements/ on a special diet?
No Yes Don't know
If yes, please state all supplements/diets: _____

S. Does your child have or has he/she had any significant illness, medical disability or condition?
No Yes Don't know
If yes, please state: _____

Parent satisfaction survey

1. **Overall program satisfaction**

   a. What was the most helpful aspect of the program?

   b. What was the least helpful aspect of the program?

2. **Usefulness of the program format**

   Please rate how useful you found each component of the program:

   a. Pre-course training

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

   b. Scripted Manuals

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

   c. Copy of student manual

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

   d. Powerpoints

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

   e. Videos

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

   f. Role-play/practice

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

   g. Component checklist

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

h. Weekly feedback sessions

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

i. Implementation checklist

Very helpful	Helpful	Neutral	Unhelpful	Very Unhelpful
☐	☐	☐	☐	☐

3. <u>Perceived changes following the program</u>

a. What changes, if any, in your parenting have you noticed since the course?

b. What changes, if any, have occurred on your interest level in your child's education?

c. What changes, if any, have you noticed in your communication with your child's teachers?

4. <u>Perceived understanding and usability of the program.</u>

a. How easy was it to understand the instructor manual?

b. How easy was it to use the instructor manual?

5. **<u>Please rate the following items were:</u>**

a. How easy/ hard was it to understand ABA

Very easy	Easy	Neutral	Hard	Very Hard
☐	☐	☒	☐	☐

b. How easy/ hard was it to teach the modules

Very easy	Easy	Neutral	Hard	Very Hard
☐	☐	☐	☐	☐

c. How appropriate is it to use ABA with children with autism

Very appropriate	Appropriate	Neutral	Inappropriate	Very Inappropriate
☐	☐	☐	☐	☐

d. How confident do you feel using the ABA skills in this course

Very confident	Confident	Neutral	Unconfident	Very Unconfident
☐	☐	☐	☐	☐

6. <u>Suggestions for program</u>

a. What else would you like to have in the program?

b. Any further suggestions?

c. How likely are you to recommend this program to a friend?

Very likely	likely	Neutral	Unlikely	Very unlikely
☐	☐	☐	☐	☐

ABA Strategy Rating Form

- Please place a TICK (√) in the box next to each strategy you found useful.
- Please a CROSS (X) next to any you found unhelpful or a problem.
- Please leave blank any you didn't use or don't have an opinion on.

☐Continuous measurement: Taking frequency and duration data on behaviours.

☐ Discontinuous measurement: Taking time sampling data on behavior

☐ Trial based preference assessment: Presenting 2 items at a time and recording the selection of items.

☐ Functional Assessment. Collecting ABC data on inappropriate behaviours.

☐ Prompt and prompt fading: Systematically selecting, applying and fading away prompts when teaching a new skill.

☐ Discrete trial training: Using a discrete trial format to teach new skills.

☐ Task-analysis: Breaking down a skill into individual, sequential steps.

☐ Chaining Procedures: Using forwards or backwards chaining based on a task analysis

☐ Differential reinforcement: Delivering higher levels of reinforcement for greater levels of effort from the student.

☐ Wait: Systematically teaching your student to wait for reinforcement

☐ Individual token economy: Using a token board to work individually with a student.

Student Pre-Course Questionnaires

A. What field did you study in university?

1. ☐ Psychology
2. ☐ Speech Pathology
3. ☐ Education
4. ☐ Defectology
5. ☐ Special Education
6. ☐Other: _____

B. I am

1. ☐ Male
2. ☐ Female

C. What is your age? _____ years old

D. What is the highest level of education you received?

1. ☐ Secondary school
2. ☐ Associates degree
3. ☐ bachelors degree
4. ☐ masters degree

E. I have had significant/considerable interactions with a person with a disability/autism:

1. ☐ None 2. ☐ A little 3. ☐ Average 4. ☐ Good 5. ☐ Significant

F. I have had the following level of training on educating students with disabilities/autism:

1. ☐ None 2. ☐ A little (up to 10 hours) 3. ☐ Some (10 hours) 4. ☐ Good (11-39 hours) 5. ☐ High (40 or more)

G. My knowledge of the local legislation or policy as it pertains to children with disabilities is:

1. ☐ None 2. ☐ Poor 3. ☐ Average 4. ☐ Good 5. ☐ Very Good

H. My level of confidence in teaching students with disabilities is:

1. ☐ Very Low 2. ☐ Low 3. ☐ Average 4. ☐ High 5. ☐ Very High

I. I have been teaching children with disabilities for:

1. ☐ Less than a year 2. ☐ 1-3 years 3. ☐ 4-5 years 4. ☐ 5-10 years 5. ☐ More than 10 years

J. My level of knowledge of Applied Behaviour Analysis (ABA) is:

1. ☐ None 2. ☐ Low 3. ☐Some 4. ☐High (formal training)

K. If you answered low-high on the previous question, what is your opinion on the appropriateness of its use with children with disabilities/autism?

1. ☐ Inappropriate 2. ☐ Indifferent/ No Opinion 3.☐ Appropriate

Student – Final Feedback Form

How easy was it for you to learn and use ABA strategies?

Very easy		Neutral		Very difficult
☐	☐	☐	☐	☐

How useful were the practice activities sessions in class?

Very useful		Neutral		Not useful
☐	☐	☐	☐	☐

How useful were the pre-class readings?

Very useful		Neutral		Not useful
☐	☐	☐	☐	☐

What effect did parents co-instructing the course have on you?

A positive effect		No effect		A negative effect
☐	☐	☐	☐	☐

Would you recommend this course to other students?

Definitely Yes		Neutral		Definitely not
☐	☐	☐	☐	☐

How likely are you to use the ABA skills in your future job?

Very likely		Neutral		Very unlikely
☐	☐	☐	☐	☐

How Prepared to you feel to use these strategies?

Very prepared		Neutral		Very unprepared
☐	☐	☐	☐	☐

Appendix C. Data collection sheet for trainees to use during skills assessments.

Trainee Data Collection Sheet for Role-Play Scenarios

Name: _____

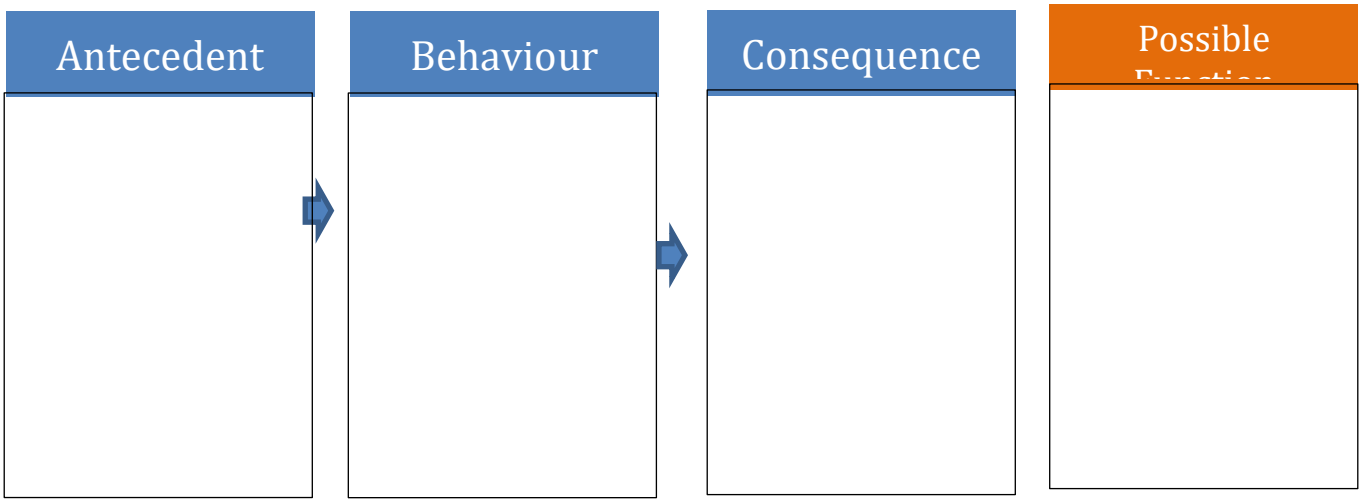
1. Preference Assessment

Potential reinforcers: _____

Trial 1		
Trial 2		
Trial 3		

Reinforcer hierarchy: 1. _____ 2. _____3. _____

2. Functional Behaviour Assessment



3. Most-to-Least Prompting

Target Behaviour:
Number of levels in the hierarchy:

Trial	Prompt type	Prompt description
1		
2		
3		
4		

Data Collection:

Trial	1	2	3	4

Prompt level given				

Prompt Key:

FP	PP	M	G	Vis	Ver	+
Full physical	Partial Physical	Model	Gestural	Visual	Verbal	Independent

4. Discrete Trial Teaching

Sd:_____

Trial	Target	Prompt	Response	Error Correction
1	airplane dog	None Verbal Gestural Physical	Correct Incorrect	Yes No
2	airplane dog	None Verbal Gestural Physical	Correct Incorrect	Yes No
3	airplane dog	None Verbal Gestural Physical	Correct Incorrect	Yes No
4	airplane dog	None Verbal Gestural Physical	Correct Incorrect	Yes No
5	airplane dog	None Verbal Gestural Physical	Correct Incorrect	Yes No

Total Correct: /5

5. Task Analysis

Scenario 1:

Task: _____

Task Analysis

1._____

2. _____

3. _____

4. _____

5. _____

Type of Chaining:_____

Scenario 2:

Task: _____

Task Analysis

1._____

2. _____

3. _____

4. _____

5. _____

Type of Chaining:_____

6. Wait

Trial	Student behaviour	Teacher Response
1	Request_____	
2	Request_____	
3	Request_____	
4	Request_____	
5	Request_____	

Appendix D. Consent forms and Information sheets

CONSENT FORM FOR PARENTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Autism and ABA in Kazakhstan
Department: Psychology and Human Development
Name and Contact Details of the Researcher(s): Erin Moran, erin.moran.16@ucl.ac.uk, [redacted]
Name and Contact Details of the UCL Data Protection Officer:
_____
This study has been approved by the UCL Research Ethics Committee: Project ID number:
_____

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time. **I confirm that I understand that by ticking/initialing each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialed boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

		Tick Box
1.	*I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction. I would like to take part in the ABA and autism training programme.	
2.	*I consent to the processing of my personal information age, gender, income and child characteristics. I understand that such information will be handled in accordance with all applicable data protection legislation.	
3.	*I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	
4.	*I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
5.	*I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
6.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
7.	I understand the direct/indirect benefits of participating.	
8.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study.	

9.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
10	I agree that my anonymised research data may be used by others for future research. No one will be able to identify you when this data is shared.	
11	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
12	I consent to my participation being audio/video recorded and understand that the recordings will be stored anonymously, using password-protected software and will be used for training, quality control, audit and specific research purposes.	
13	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
14	I hereby confirm that: (a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and (b) I do not fall under the exclusion criteria.	
15	I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.	
16	I am aware of who I should contact if I wish to lodge a complaint.	
17	I voluntarily agree to take part in this study.	
18	Use of information for this project and beyond I would be happy for the data I provide to be archived at UCL. I understand that other authenticated researchers will have access to my anonymised data.	

If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.

Yes, I would be happy to be contacted in this way
No, I would not like to be contacted

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of witness (If applicable)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

CONSENT FORM FOR STUDENTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Autism and ABA in Kazakhstan
Department: Psychology and Human Development
Name and Contact Details of the Researcher(s): Erin Moran, erin.moran.16@ucl.ac.uk, [redacted]
Name and Contact Details of the UCL Data Protection Officer:
_____
This study has been approved by the UCL Research Ethics Committee: Project ID number:
_____

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	*I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction. I would like to take part in the ABA and autism training programme.	
2.	*I consent to the processing of my personal information age, gender, occupation and specialty for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation.	
3.	*I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	
4.	*I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
5.	*I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
6.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
7.	I understand the direct/indirect benefits of participating.	
8.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study.	
9.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	

10	I agree that my anonymised research data may be used by others for future research. No one will be able to identify you when this data is shared.	
11	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
12	I consent to my participation being audio/video recorded and understand that the recordings will be stored anonymously, using password-protected software and will be used for training, quality control, audit and specific research purposes.	
13	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
14	I hereby confirm that: (c) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and (d) I do not fall under the exclusion criteria.	
15	I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.	
16	I am aware of who I should contact if I wish to lodge a complaint.	
17	I voluntarily agree to take part in this study.	
18	Use of information for this project and beyond I would be happy for the data I provide to be archived at UCL. I understand that other authenticated researchers will have access to my anonymised data.	

If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.

	Yes, I would be happy to be contacted in this way	
	No, I would not like to be contacted	

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of witness (If applicable)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Participant Information Sheet For Parent Participants

UCL Research Ethics Committee Approval ID Number: _____

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Autism and ABA in Kazakhstan
Department: IOE Department of Psychology and Human Development.
Name and Contact Details of the Researcher(s): Erin Moran, erin.moran.16@ucl.ac.uk, [redacted]
Name and Contact Details of the Researcher Supervisor: Dr. Jennifer Allen, Jennifer.allen@ucl.ac.uk

1. Invitation Paragraph

We invite you to participate in a research project, conducted by Erin Moran (PhD student in Psychology and Human Development), under the supervision of Dr Jennifer Allen and Dr William Mandy at the UCL Institute of Education. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please ask us if there is anything that is not clear or if you would like more information.

2. What is the project's purpose?

We would like to investigate whether an undergraduate course, taught by parents of children with autism, can change attitudes towards inclusive education. We also aim to determine if this is an effective method for teaching fundamental skills based on Applied Behavior Analysis (ABA). The information gathered in this study will help to extend our knowledge about factors that influence inclusive education, the methodologies we use to research them, and guide the development and/or improvement of training for undergraduate and postgraduate students and professionals.

3. Why have I been chosen?

We are looking for parents of children with Autism Spectrum Disorder. It is important that the parent who participates is the primary caregiver. This research is not suitable for parents with a severe mental health disorders. The parent must be comfortable speaking in front of a group of people and leading a discussion. It will be necessary for the parent to have transportation to the courses at Kazakhstan American Free University. The courses will be conducted in Russian, so Russian fluency is a requirement

4. Do I have to take part?

No. We are pleased you have expressed an interest in taking part, but you should only participate if you want to do so. If you do decide to take part, you are free to withdraw at any time and without giving a reason. If you do not wish to participate in this research it will not affect your child's services at the centre.

5. What will happen to me if I take part?

The researcher will visit Kazakhstan and provide an intensive training on the course content at a local centre. Training will also be provided on how to be an effective public speaker. After this initial training, you will co-instruct a six week course, providing lectures and leading discussions. The course will meet two times a week for 1-2 hours. Before and after the course you will be asked to complete questionnaires. The questionnaire will ask you questions about your attitudes and knowledge of autism and your child's access to services. You will also be asked to provide feedback on the course. This feedback will be very helpful in the future revision and use of the training

6. Will I be recorded and how will the recorded media be used?

The audio and/or video recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

7. What are the possible disadvantages and risks of taking part?

You may experience some discomfort discussing your experience as a parent of a child with autism. If you feel any questions or discussion are too personal, you can decline to answer the question. You have also feel some anxiety around presenting the course. Pre-course training will help prepare to you present the sessions and the researcher will be available for ongoing support.

8. What are the possible benefits of taking part?

The information you and other parents provide could help to further the knowledge field of autism and ABA in Kazakhstan. As you learn about ABA in the course, you may begin to use it with your own child and see significant improvements in skills and inappropriate behaviors. We hope that the activity will be interesting for both parents and university students.

9. What if something goes wrong?

In the even that you have any complaints or a serious concern regarding the project, you should first contact the researcher, Erin Moran. Every effort will be made to resolve an issues. However, if the research is not able to handle the complaint to your satisfaction, you should contact the Chair of the UCL Research Ethics Committee- ethics@ucl.ac.uk**.**

10. Will my taking part in this project be kept confidential?

All of the information we collect about you will be kept strictly confidential. Any contact information, such as your name and address, will be kept separately from the other information you provide. In this way, all information collected will remain anonymous. All information will be stored according to the requirements of the Data Protection Act (1998). Any video recordings will be encrypted and password protected. Access to the information will be restricted to the study team. The only time we will tell anyone else about what you have said, giving your name, is if we think someone risks being hurt. We will talk to you about this first.

11. Limits to confidentiality

- Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case we would inform you of any decisions that might limit your confidentiality.

12. What will happen to the results of the research project?

Once we have collected information from the course we will write a report on the study findings. You will have the option to request a copy of the report, which will be sent to you via email if you opt in. The information will be used to complete the primary researcher's doctoral thesis.
This project will be reviewed by the IOE Ethics Committee. All researchers on this project will undergo formal review by DBS (Disclosure and Barring Service) to work with children.

13. Data Protection Privacy Notice

Notice:

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk**.**

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be [the provision of your consent.] You can

provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

14. Contact for further information

Please ask us if there is anything that is not clear or if you would like more information. If you agree to take part in the study, please sign the consent form overleaf.

	Erin Moran	Dr. Jennifer Allen
Email:	erin.moran.16@ucl.ac.uk	Jennifer.allen@ucl.ac.uk
Mobile:	[redacted]	

You will be given a copy of this information sheet before signing a consent form.

Thank you for reading this information sheet and for considering to take part in this research study.

Participant Information Sheet For Student Participants

UCL Research Ethics Committee Approval ID Number: _____

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Autism and ABA in Kazakhstan
Department: IOE Department of Psychology and Human Development.
Name and Contact Details of the Researcher(s): Erin Moran, erin.moran.16@ucl.ac.uk, [redacted]
Name and Contact Details of the Researcher Supervisor: Dr. Jennifer Allen, Jennifer.allen@ucl.ac.uk

14. Invitation Paragraph

We invite you to participate in a research project, conducted by Erin Moran (PhD Psychology and Human Development), under the supervision of Dr Jennifer Allen and Dr William Mandy at the UCL Institute of Education. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please ask us if there is anything that is not clear or if you would like more information.

15. What is the project's purpose?

We would like to investigate whether a training course, taught by parents of children with autism, is an effective method for teaching fundamental skills based on Applied Behavior Analysis (ABA). We also aim to determine the programme can change attitudes towards inclusive education. Information gained from this study will help to extend our knowledge about factors that influence inclusive education, the methodologies we use to research them, and potentially help in the development and/or improvement of training for undergraduate and postgraduate students and professionals.

16. Why have I been chosen?

We are looking for undergraduate and graduate students enrolled in a university in Ust-Kamenogorsk. Students in psychology, defectology or related departments are welcome to participate. Special needs teachers are also invited to attend

17. Do I have to take part?

Yes. In order to enroll in the course you will need to be willing to participate in the research project. If you do decide to take part, you are free to withdraw at any time and without giving a reason.

18. What will happen to me if I take part?

When you begin the course you will complete several questionnaires. These questionnaires are confidential and will not affect your grade or placement in the programme. You will then complete the course that will be co-instructed by parents of children with autism. As part of the course, you will be taught specific teaching strategies. For your final examination you will be asked to demonstrate these skills in a role-playing situation. This role play may be video-recorded. At the conclusion of the study you will be asked to complete several questionnaires and you may once again be asked to participate in a focus group to discuss your feelings about children with disabilities.

19. Will I be recorded and how will the recorded media be used?

The audio and/or video recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

20. What are the possible disadvantages and risks of taking part?

During this course you will be required to discuss potentially sensitive topics, such as what it is like to parent or teach a child with autism. You will also be expected to practice new teaching strategies in role-play situations. You may feel uncomfortable participating in the practice sessions, however you will be given the support needed to complete them successfully.

21. What are the possible benefits of taking part?

The information you and other students provide could help to further the knowledge field of inclusive education in Kazakhstan. You will learn new teaching principles and strategies that can be used with students in a variety of settings. We hope that the activity will be interesting for both you and the parents.

22. What if something goes wrong?

In the even that you have any complaints or a serious concern regarding the project, you should first contact the researcher, Erin Moran. Every effort will be made to resovle an issues. However, if the research is not able to handle the complaint to your satisfaction, you should contact the Chair of the UCL Research Ethics Committee- ethics@ucl.ac.uk**.**

23. Will my taking part in this project be kept confidential?

All of the information we collect about you will be kept strictly confidential. Any contact information, such as your name and address, will be kept separately from the other information you provide. In this way, all information collected will remain anonymous. All information will be stored according to the requirements of the Data Protection Act (1998). Any video recordings will be encrypted and password protected. Access to the information will be restricted to the study team. The only time we will tell anyone else about what you have said, giving your name, is if we think someone risks being hurt. We will talk to you about this first.

24. Limits to confidentiality

- Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case we would inform you of any decisions that might limit your confidentiality.

25. What will happen to the results of the research project?

Once we have collected information from the course we will write a report on the study findings. You will have the option to request a copy of the report, which will be sent to you via email if you opt in. The information will be used to complete the primary researcher's doctoral thesis.
This project will be reviewed by the IOE Ethics Committee. All researchers on this project will undergo formal review by DBS (Disclosure and Barring Service) to work with children.

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Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be [the provision of your consent.] You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

14. Contact for further information

Please ask us if there is anything that is not clear or if you would like more information. If you agree to take part in the study, please sign the consent form overleaf.

	Erin Moran	Dr. Jennifer Allen
Email:	erin.moran.16@ucl.ac.uk	Jennifer.allen@ucl.ac.uk
Mobile:	[redacted]	

You will be given a copy of this information sheet before signing a consent form.

Thank you for reading this information sheet and for considering to take part in this research study.

Appendix E. Measures from main study.

Family Empowerment Scale (FES)

Instructions: Below are 34 statements that describe how a parent or caregiver of a child with an emotional, behavioral and/or developmental challenges may feel about his or her situation. For each statement, please circle the response that best described how the statement applies to you.					
FES Statements	Not True at all	Mostly not True	Somewhat True	Mostly True	Very True
1. I feel that I have a right to approve all services my child receives	1	2	3	4	5
2. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
3. I feel I can have a part in improving services for children in my community.	1	2	3	4	5
4. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
5. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
6. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
7. I know what to do when problems arise with my child.	1	2	3	4	5
8. I get in touch with my legislators when important bills or issues concerning children are pending.	1	2	3	4	5
9.I feel my family life is under control	1	2	3	4	5
10. I understand how the service system for children is organized.	1	2	3	4	5
11. I am able to make good decisions about what services my child needs.	1	2	3	4	5
12. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5
13. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
14. I have ideas about the ideal service system for children.	1	2	3	4	5
15. I help other families get the services they need.	1	2	3	4	5
16. I am able to get information to help me better understand my child.	1	2	3	4	5

FES Statements	Not True at all	Mostly not True	Somewhat True	Mostly True	Very True
17. I believe that other parents and I can have an influence on services for children.	1	2	3	4	5
18. My opinion is just as important as professionals' opinions in deciding what services my child needs.	1	2	3	4	5
19. I tell professionals what I think about services being provided to my child.	1	2	3	4	5
20. I tell people in agencies and government how services for children can be improved.	1	2	3	4	5
21. I believe I can solve problems with my child when they happen.	1	2	3	4	5
22. I know how to get agency administrators or legislators to listen to me.	1	2	3	4	5
23. I know what services my child needs.	1	2	3	4	5
24. I know what the rights of parent and children are under the special education laws.	1	2	3	4	5
25. I feel that my knowledge and experience as a parent can be used to improve services for children and families.	1	2	3	4	5
26. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5
27. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
28. When necessary, I take the initiative in looking for services for my child and family.	1	2	3	4	5
29. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
30. I have a good understanding of the services system that my child is involved in.	1	2	3	4	5
31. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
32. Professionals should ask me what services I want for my child.	1	2	3	4	5
33. I have a good understanding of my child's disorders.	1	2	3	4	5
34. I feel I am a good parent.	1	2	3	4	5

Sentiments and Attitudes Toward Inclusive Education-Revised (SACIE-R)

The following statements pertain to inclusive education which involves students from a wide range of diverse backgrounds and abilities with their peers in regular schools that adapt and change the way they work in order to meet the needs of all students.

Please circle the response which best applies to you.

SD	D	A	SA
Strongly Disagree	Disagree	Agree	Strongly Agree

1	I am concerned that students with disabilities will not be accepted by the rest of the class.	SD D A SA
2	I dread the thought that I could eventually end up with a disability.	SD D A SA
3	Students who have difficulty expressing their thoughts verbally should be in regular classes.	SD D A SA
4	I am concerned that it will be difficult to give appropriate attention to all students in an inclusive classroom.	SD D A SA
5	I tend to make contacts with people with disabilities brief and I finish them as quickly as possible.	SD D A SA
6	Students who are inattentive should be in regular classes.	SD D A SA
7	I am concerned that my workload will increase if I have students with disabilities in my class.	SD D A SA
8	Students who require communicative technologies (Braille/sign language) should be in regular classes.	SD D A SA
9	I would feel terrible if I had a disability.	SD D A SA
10	I am concerned that I will be more stressed if I have students with disabilities in my class.	SD D A SA
11	I am afraid to look directly at a person with a disability.	SD D A SA
12	Students who frequently fail exams should be in regular classes.	SD D A SA
13	I find it difficult to overcome my initial shock when meeting people with severe physical disabilities.	SD D A SA
14	I am concerned that I do not have the knowledge and skills required to teach students with disabilities.	SD D A SA
15	Students who need an individualized academic program should be in regular classes.	SD D A SA

Appendix F. ABA and autism knowledge exam.

1. Autism spectrum disorder (AUTISM) is caused by vaccines
    a. True
    b. False

2. AUTISM is caused by mothers who are 'cold' and detached.
    a. True
    b. False

3. AUTISM refers to:
    a. One specific disorder
    b. A highly rare condition
    c. Something that only exists in children
    d. A range of conditions with common characteristics
4. There is one cause for autism:
    a. True
    b. False
5. There is a cure for autism:
    a. True
    b. False
6. It is very easy for children with autism and their families to get treatment and services.
    a. True
    b. False
7. Who conducted the famous experiment with a dog that discovered classical conditioning?
    a. B. F. Skinner
    b. John B. Watson
    c. Ivan Pavlov
    d. Leo Kanner
8. What type of behaviour is learned?
    a. Reflexive Behaviour
    b. Respondent behaviour
    c. Classical Behaviour
    d. Operant behaviour
9. Applied Behaviour Analysis (ABA) is only used with young children with autism.
    a. True
    b. False
10. What kind of data tells you how long a behaviour occurred for?
    a. Rate
    b. duration
    c. frequency
    d. momentary time sampling
11. Occurs when a new stimuli is paired with another stimuli to elicit a response.
    a. Reflexive conditioning
    b. Respondent conditioning
    c. Classical Conditioning
    d. Operant conditioning
12. The science of understanding and improving socially significant behaviours is:
    a. ABA

b. Developmental Psychology
c. Cognitive psychology
d. Social Psychology

13. When does reinforcement occur?
    a. Before the behaviour
    b. During the behaviour
    c. After the behaviour
    d. The following day
14. Reinforcement works better than punishment and is used primarily during ABA therapy.
    a. True
    b. False
15. When using continuous reinforcement, how often do you deliver reinforcement?
    a. Never
    b. For every response
    c. For every other response
    d. When you think the student needs it
16. Getting paid every Friday is an example of what schedule of reinforcement?
    a. Fixed interval
    b. Fixed ratio
    c. Variable interval
    d. Variable ratio
17. What is not true about reinforcement?
    a. Everyone has different reinforcers
    b. Reinforcers can change
    c. Reinforcers increase the future probability of a behaviour
    d. Stickers are always reinforcers
18. When teaching a new skill, how when should you deliver reinforcement?
    a. At the end of the day
    b. After the student sits quietly
    c. Never
    d. Immediately
19. What is the definition of 'behaviour'?
    a. Human actions and movements
    b. All stimuli in the environment
    c. They way in which we act
    d. An observable and measurable act; includes everything that people do
20. What is not one of the three key aspects in analysing behaviour?
    a. Consequence
    b. Response
    c. Antecedent
    d. Behaviour
21. What is not a function of behaviour?
    a. Control
    b. Tangible
    c. Attention
    d. Escape
22. How do you determine the function of behaviour?
    a. Preference Assessment
    b. Functional Behaviour Assessment

c. Questionnaire
d. Ask the person

23. After a child screams, his mother reprimands him. What is a possible function?
    a. Control
    b. Tangible
    c. Attention
    d. Escape
24. Behaviour Analysis is concerned with determining:
    a. Why behaviour occurs
    b. What repressed experiences we have
    c. Attachment
    d. Self-report of behaviour
25. What is not an example of a prompt?
    a. Verbal
    b. Gestural
    c. Intellectual
    d. Physical
26. We use prompts:
    a. To help a student learn a new skill
    b. To save time because the student cannot do it themselves
    c. Forever
    d. Always
27. Once we introduce a prompt we should:
    a. Use it forever
    b. Use it with all students
    c. Plan to fade it
28. Shaping should be combined with prompting.
    a. True
    b. False
29. When using shaping, we only provide reinforcement for the independent display of the target behaviour.
    a. True
    b. False
30. Shaping should be:
    a. Easy
    b. Fast
    c. Errorless
    d. Boring
31. What is a method of teaching in simplified, structured steps?
    a. Shaping
    b. Discrete Trial Training
    c. Prompting
    d. Lecturing
32. A discriminative stimulus (Sd) is:
    a. A stimulus that occurs before the behaviour
    b. The behaviour
    c. A consequence
    d. A prompt
33. What should you do if a student makes an error during DTT?
    a. Ignore it

b. Reprimand them
c. Tell them the correct answer
d. Go through error correction

34. Backwards chaining is always better than forwards chaining.
    a. True
    b. False
35. Chaining is used when teaching a:
    a. Task Analysis
    b. Error Correction
    c. DTT
    d. Preference Assessment
36. Forwards chaining involves:
    a. Teaching the last step first
    b. Teaching the beginning step first
    c. Teaching the middle step first
    d. Teaching the steps in a random order
37. Communication and language delays are common in children with AUTISM.
    a. True
    b. False
38. What is not a key aspect of communication?
    a. That it is understood by the community
    b. That is involves speech
    c. That is it directed towards another person
    d. That the other person provides a direct or social reward
39. What is the first functional communication operant you should teach?
    a. Labeling
    b. Requesting
    c. Writing
    d. Echoing
40. When teaching 'yes' it is good to use:
    a. Preferred items
    b. Neutral items
    c. Items the child has never seen
    d. Hypothetical questions
41. What is PECS?
    a. A picture point system
    b. Not a communication modality
    c. Picture exchange communication system
    d. Sign language system

42. Who first coined the 5 verbal operants?
    a. Lovaas
    b. Kanner
    c. Pavlov
    d. Skinner
43. When teaching help, we want to establish what kind of situation?
    a. Fun
    b. Neutral
    c. Slightly frustrating
    d. Very frustrating

44. When teaching ‘help’ it is best to vary the items/situations the student needs help with.
    a. True
    b. False
45. When teaching ‘wait’ we want to make sure we are still provide the reinforcer
    a. 1/5 times
    b. 2/5 times
    c. 3/5 times
    d. 4/5 times
46. When teaching ‘wait’ it is good to be unpredictable in which times you will give the student the reinforcer and which times you will ask them to wait.
    a. True
    b. False
47. What is not one of the 3 ways suggested strategies to help your student accept ‘no’?
    a. Offer an alternative
    b. Show an empty container
    c. Say ‘yes’ but only if they do something first
    d. Explain to them why it is a ‘no’
48. If a student has a temper tantrum after you say they cannot have their toy, you should give them the toy so they stop screaming.
    a. True
    b. False

Appendix G. Confidentiality agreement for translators.

CONFIDENTIALITY AGREEMENT - TRANSLATOR

I, _____ have been engaged as a translator on the project ABA and Autism in Kazakhstan, and may be required to interpret, translate or transcribe interviews or written forms in this role. In carrying out these activities, I undertake to communicate information fully and faithfully, to the best of my abilities.

I understand that all information provided by participants is confidential, and I agree not to use or disclose this information except as required in the course of my duties as a research assistant. I also undertake to store any records of interviews securely as directed by the researcher, and to destroy any copies of these records remaining in my possession once my involvement in the project ends.

_____ _____

Translator signature Date