

**Parental Reports on the Efficacy of Applied Behavior
Analysis based intervention for children with Autism
Spectrum Disorder in UAE.**

تقارير الأهل حول فعالية تحليل السلوك التطبيقي بناءً على التدخُّل بحالات
الأطفال الذين يعانون من اضطراب طيف التوحد في دولة الإمارات العربية
المتحدة

by

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Abstract:

This study was conducted to investigate the views of parents of children with Autism Spectrum Disorder regarding the efficacy of intervention based on Applied Behavior Analysis, for their child, in United Arab Emirates.

Data was collected via electronic survey questionnaire, parent interviews and literature research. Although the findings of this study are positive, it highlighted the gaps in the field and the need for further research in order to create more availability of intervention services and establish regulation in the area of services for Autism and specifically for Applied Behavior Analysis in UAE.

خلاصة:

تم إجراء هذه الدراسة للتحقق من وجهات نظر أهالي الأطفال الذي يعانون من اضطراب طيف التوحد، من حيث كفاءة التدخل بناءً على تحيل السلوك التطبيقي للأطفال في دولة الإمارات العربية المتحدة. وقد تمّ جمع البيانات من خلال استبيانات الاستقصاء الإلكترونية والمقابلات مع الأهالي والبحوث في المراجع. ورغم أن نتائج هذه الدراسة كانت إيجابية، فقد أثبتت وجود فجوات في هذا المجال، والحاجة إلى بحث آخر لغرض تحقيق المزيد من توفّر خدمات التدخل ووضع أنظمة في مجال خدمات التوحد وخاصة لتحليل السلوك التطبيقي في دولة الإمارات العربية المتحدة.

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Chapter 1: INTRODUCTION:

1.1 Background and Purpose of study:

The prevalence of Autism is growing worldwide. According to a surveillance summary report released on April 1, 2016, by Centre for Disease Control & Prevention and conducted by Autism & Developmental Disabilities Monitoring Network (ADDM) for the period of 2012, 1 in 68 have been identified with Autism Spectrum Disorders (ASD) in the United States. Christensen, DL et al (2012) in the report say that,

“For 2012, the combined estimated prevalence of ASD among the 11 ADDM Network sites was 14.6 per 1,000 (one in 68) children aged 8 years. Estimated prevalence was significantly higher among boys aged 8 years (23.6 per 1,000) than among girls aged 8 years (5.3 per 1,000).”

As reported by World Health Organization (2016), this number is estimated 1 in 60 amongst the worldwide population; this being an average figure; reports have shown variation across studies.

While there is much debate regarding the causes of Autism, its treatment remains a challenge for families and communities. Identifying treatments that have a basis in science and research is an additional challenge to families. Looking at the experiences of parents of children diagnosed with autism, it is seen that, due to the fact that Autism has no known medical cure, parents end up experiencing a large variety of providers with different levels of promises and commitment to scientifically validated treatments. Research suggests a biological basis as a cause for Autism. Although studies claim

(Celiberti. D., et al, 2004) that there are currently no scientifically-validated medical treatments to address the core deficits of Autism; many parents still believe in the medical possibility for a treatment for at least a few, if not all the deficits caused due to Autism. These treatments have included medications and various alternative therapies.

Greene. V., et al (2006) point out that many such treatments for Autism exist and are used by parents of children with ASD. These treatments are highly supported and promoted by their developers, yet most of them are not subjected to sound scientific research.

Similarly, at present in UAE, there are a variety of interventions available for persons with ASD, these consist of alternative diets, nutritional supplements, biomedical intervention, speech & language therapy, occupational Therapy, medication and Applied Behavior Analysis (Kelly, M., et al 2016). In their journey towards treatment for autism for their child, parents in UAE will quite possibly encounter Applied Behavior Analysis (ABA).

The field of Applied Behavior Analysis (ABA) has evolved greatly in recent decades. Data based literature supporting the interventions for persons with Autism based on principles of ABA are abundant (Celiberti. D., et al, 2004). There is growing evidence and international support for ABA-based interventions as an effective intervention for ASD. (Wong, C., et al 2015)

ABA has been known to provide an evidence-based approach to student centered education. Overall, World Health Organization (2016) & Center for Disease Control report (2012) notes that it is important to identify scientific & evidence-based treatments that carry social impact. These should be treatments; that families and persons with Autism, find beneficial to their daily lives, and are easy to access and administer.

According to the Ministry of Education of UAE (n.d); United Arab Emirates is a 45 years old country made up of seven emirates. Oil exploration brought about affluence in the country through enhanced trade and commerce. Education systems in UAE were at first, based on traditional styles, and then over passage of time and advancement in resources and technology, it has developed to its present systematic form. Formal School system was launched in UAE when it was declared a federation on 2nd December 1971.

Although the provision of Special Education programs and services in its educational system since 1979, albeit, concrete progress in this area has been noticed only since 2006 after UAE's adoption of United Nation's Convention on Rights for Persons with Disabilities.

Formal statistics on the prevalence of Autism in UAE, is limited to a study conducted by V, Eapen et al in 2007. Due to lack of availability for prevalence data for ASD in UAE, I have conducted this research study with the assumption that prevalence of ASD is at least the same as statistics worldwide, if not more. Going with this assumption and due

to the paucity of any other epidemiological data, it is being said that there may be a similar prevalence of children with ASD in UAE.

Although there is no federal policy for licensing for ABA service or service providers in UAE there are at least 11 special needs centres that implement ABA-based intervention programs for children with Autism (Kelly, M., et al 2016). It thus becomes important to evaluate treatment efficacy of ABA intervention in UAE from the perspective of the parents of children with ASD. The extent to which parents & families find a treatment effective will support the social validity of a treatment.

An additional motivation to conduct this study comes from the fact that I was recently involved in a research based review, quoted above, that was conducted across the Gulf Council Countries (GCC), (Saudi Arabia, Qatar, Oman, Bahrain, Kuwait and UAE), to examine the past, present and future status of ABA services for Autism in GCC. This study was published in Journal for Autism and Development Disorders in June 2016. The aims of this paper were to provide a brief overview of autism and ABA clinical services and educational opportunities and to investigate the relevant research published from each of the six states of the GCC. (Kelly, M., et al 2016)

Taking the next step forward in relevance to my experience and motivation is to measure the efficacy of ABA-based interventions provided in UAE based on the perspective of the parents of children with ASD. As social validity refers to the social importance and acceptability of goals, procedures and outcomes of treatment provided; it has been the

driving factor for this study. Grandstaff-Beckers, G. (2013) point out that the intervention received by persons with Autism has direct impact on their lives and lives of persons around them. It is therefore, important to understand the perception of the intervention as felt, observed and understood by them, rather than by clinicians or therapists.

The recent release of this study and the growing interest in Applied Behavior Analysis as an intervention for ASD; sets the stage to investigate the perspective of the parents, on the efficacy of Applied Behavior Analysis based intervention, for their children on the Autism Spectrum in UAE.

1.2 Research Questions:

1. Do parents report that there is a positive effect of ABA intervention for their child and family?
 - 1.1 How does a parent describe positive effect of intervention for their child and family?
 - 1.2 What do parents see as barriers in the effectiveness of ABA intervention?
 - 1.3 What is the overall experience of the parents in procuring and using ABA intervention for their child?

Chapter 2.

LITERATURE REVIEW:

This literature review is designed with a structure to individually tackle each component of the research in question. It begins with defining and attempting to examine the present status of Autism Spectrum Disorder, Applied Behavior Analysis and the UAE context for ABA and ASD.

2.01 Autism Spectrum Disorder:

According to American Psychological Association (APA), Autism is the most severe developmental disability. Appearing within the first three years of life, autism involves impairments in social interaction — such as being aware of other people’s feelings — and verbal and nonverbal communication. Some people with autism have limited interests, strange eating or sleeping behaviors or a tendency to do things to hurt themselves, such as banging their heads or biting their hands.

Kanner. L (1943) gave a detailed description of 11 children who had a variety of disturbances in their development at different levels, and yet had unique common features making it a syndrome that had never before been reported. This led to the initial definition of Autism. For many years; after Kanner. L., defined Autism in 1943, it was understood to be a rare condition with a very small prevalence of about 2-4 persons per 10,000. Since Kanner’s definition of ASD, the emphasis in Autism has been on the lack of social interaction, communication and presence of repetitive and ritualistic behaviors.

(Gilliam J. et al, 2000). According to Wolff. S (2004); “Autism has been puzzling, fascinating and massively researched since its discovery.” Autism is a neurodevelopmental disorder that affects all aspects of functioning of the individual.

Defining and understanding Autism has been a constantly evolving process

Autism Spectrum Disorders are a group of neurodevelopmental disorders said to have deficits in social interaction, communication and have ritualistic and repetitive behaviors.

The Diagnostic & Statistical Manual (DSM) is the manual used by clinicians and researchers to diagnose and classify mental disorders. Over the years the term and definition of Autism has changed. In the earlier DSM, Autism was not well understood and terms like “Autistic-type” behaviors was used. It was first placed under mental health disorders and then later moved under neurodevelopmental disorders. It was classified as Childhood schizophrenia and only most severely impacted were given this diagnosis.

According to the classification specified in DSM-4, Autistic Disorder, Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, and Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS) were all included under one broad ASD umbrella for diagnosis. Prior to that, in DSM-3, Autism was labeled as a distinct disorder called ‘Infantile autism’ and PDD-NOS was added later. In the revised version of DSM-3 the diagnostic term changed to ‘autistic disorder and criteria were

revised to include what is well known as Triad of symptoms (impairment in socialization, communication and restricted repertoires of activities and interests), and the age of onset was specified.

Most Recently, the American Psychological Association (APA) published the 5th version of DSM – DSM-5, in 2013 after a 14 years revision process.

The DSM-5, revised the Autism diagnostic criteria and eliminated individual disorders such as Asperger's Syndrome, Rett's syndrome or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) to be replaced by one diagnosis – Autism spectrum disorder (APA 2013). In DSM-5 the specific criteria for diagnosis were also changed- Communication and social interaction deficits were merged into one area and sensory impairments were added to the area of repetitive behaviors and restricted interests. There was a clarification added to the age of onset criteria, which stated that, while symptoms should be present by age of three they may not be apparent until later. Most importantly three specific levels were added based on level of severity and need for support: Level 1 – Requiring support; Level 2- Requiring substantial support and Level 3 – Requiring Very substantial support. (Neal, D., Hattier J., 2014)

The prevalence of ASD has increased dramatically. There have been reports of rise in the incidence of ASD to over 60 per 10,000 in recent years (Wing. L., 2002). The most recent prevalence study released by CDC states in 2014 that, the Autism & Developmental Disabilities Monitoring Network (ADDM) has identified about 1 in 68

children with ASD; it further mentions that ASD is reported to occur in all racial, ethnic and socioeconomic groups and it is 4.5 times more common in boys than girls. Prevalence studies in the Arab region are extremely few, leading to the “unwarranted assumption” (Hussein.H & Taha. G., 2013) of its rare incidence in non-western countries.

According to Matson. J, & Kozolwski, A (2011); out of the various hypotheses being presented the most frequently looked at possibilities are:

1. The diagnostic criteria being widened
2. More awareness
3. Diagnosis at early ages
4. Recognition that ASD is a lifelong disorder.

Investigating the cause of Autism has been a mammoth task for many years. There is overwhelming evidence pointing towards a substantial genetic component as a cause for ASD (Bailey. A.,1995).

Although the clinical definition and diagnostic criteria has evolved in the last few decades, the actual understanding of the condition remains bewildering for most laypersons. Dillenburger. K. et al., (2012) suggest, “The term spectrum indicates that the impairments are not limited to specific symptoms but may vary across a continuum.” It is important to understand the due to the variance across a continuum; every person with ASD is affected differently and will require an individual treatment plan. When a parent

is encountered by their child's deficits, they become baffled due to the nature of presentation of the disorder. Autism is characteristic of being a spectrum of disorders that vary in severity and are at times, also associated with other disorders such as Mental retardation, epilepsy, ADHD etc. The way Autism manifests in each person is quite unique, making individualized intervention plans most pertinent. The variability within and across the skill sets of children with autism makes it difficult and perturbing for family members and at times, for clinicians. Many a times, this leads to denial, later diagnosis, and delays in procuring intervention.

According to Bartak. L., (1978), due to their "bewildering array of disturbed behaviors and disabilities" it becomes difficult for teachers to understand where to begin and what to teach.

With the scientists and researchers looking for a cause and subsequently a cure; the reality of its treatment remains to be tackled on a daily basis for families and communities across the world.

2.02: Applied Behavior Analysis:

Behavior Analysis is a discipline based on the work first done by B. F Skinner. Skinner introduced the term operant in the science of behavior analysis. Operant differentiates the behavior that "Operates" on the environment from the behaviors that "responds" to the environment. Some "operants" get selected and maintained by their consequences; this is the process called "operant conditioning". (Vargas. J., 2013)

“Applied Behavior Analysis (ABA) is the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior” (Baer, Wolf, Risley-1987).

The central idea of this definition is the reliance on scientific application of learning theory; referring to using reinforcement contingencies and other important principles to establish, strengthen or generalize socially significant behaviors and reduce undesirable behaviors. The second key feature in this definition is the idea of demonstrating efficacy of treatment. This means the intervention is evaluated for its effectiveness and modified in order to make continued progress. The most important part of the definition is the idea of “social significant behaviors to a meaningful degree”. This means behaviors selected for treatment have social significance for the participants. Behaviors such as communication, language, academics, self care, daily living, vocational, leisure, recreation etc; that go towards improving the day to day living of the participants and the society at large; and that the change that occurs is of a meaningful extent to all participants. (Cooper et al., 2007). ABA objectively measures and analyzes the variables in the environment of which the problem behaviors and appropriate behaviors are the functions; ABA focuses on this functional approach to develop effective treatments that are applicable to a wide variety for socially significant behaviors (Fisher, W., & Piazza, C., 2015)

Under the umbrella of ABA, many different treatment packages are employed. Examples include early intensive behavioral intervention, discrete trial training, pivotal

response training, incidental teaching, natural environment training, fluency based instruction, precision teaching, direct instruction and many more. ABA is the most widely recommended, scientific treatment for persons with Autism Spectrum Disorders. It has a rich and large body of empirical support that shows its efficacy in Autism Treatment. It is an objective discipline that focuses on reliable measurement and objective evaluation of observable behaviors. Granpeeshe, D., et al (2009), in their review article suggest that, the single treatment approach that garners substantial scientific support involves interventions based on principles and procedures based on ABA.

Pollitte. L. C et al (2015), a group of pediatricians, in their recent paper, acknowledge that there is substantial amount of literature to support the use of early behavioral interventions for children with Autism Spectrum Disorder. They confirm that Early Intensive Behavioral Treatment programs have been shown to improve outcomes.

Over past 60 years ABA has made notable contributions to the literature regarding Developmental Disabilities; (Axelrod, S. & Kates-McElrath, K., 2012). The Journal of Applied Behavior Analysis (JABA) and Journal of Autism & Developmental Disabilities (JADD) have numerous articles pointing towards the efficacy of ABA intervention as a treatment for ASD. Many studies that have replicated Lovaas' model of Intensive Behavioral Treatment find significant gains in IQ scores of children with ASD. (Spreckly. M., & Boyd. R. 2009; Reed, P., 2016)

ABA-based interventions have been recognized as an effective treatment by many professional and national bodies such as the Surgeon General of United States of America (NRC 2001) and Canada's Ontario's statewide Intensive Behavioral Intervention initiative. (Perry. A., 2002).

Although there is much agreement regarding efficacy of ABA treatment for ASD, there also exists some criticism and skepticism by researchers about the efficacy of ABA as treatment for ASD. This is usually in regard to the fact that a large amount of evidence in favor of ABA is from single subject designs. Although beneficial effects have been observed at group level, there are many variations in treatment outcome in individual cases. Klintwall. L., et al (2011) emphasize that “These variations may be due to child's characteristics, the impact of ASD on his skills, treatment fidelity & training level of therapists”. It is to be noted that an array of effective interventions now in use have emerged from single-subject research methods. Horner. R., et al (2005) in their book explain that interventions derived from social learning theory, medicine, social psychology, social work and communication disorders are a few examples of procedures analyzed by single-subject designs. Pediatricians Myers. S., & Johnson. P., (2007) have also noted in their paper that the effectiveness of ABA intervention in ASD has been well documented in the last 50 years of research using single-subject methodology. In contract, Rogers. S & Vismara. L (2008), contend that though evidence suggests positive impact from early behavioral intervention for children with Autism, the field seems to still be early in determining the most efficient intervention models.

Dillenburger. K., & Keenan M., (2009) make important point to be noted that ABA is not a “Therapy for Autism”, but a science based on scientifically validated principles of learning theory which are applied to people various behaviors and diagnosis, ASD being one of them.

A recent review, of which I was one of the authors, looked at the status of Applied Behavior Analysis as an intervention for Autism Spectrum Disorders in GCC and found that within Gulf Council Countries (UAE is one of the GCC countries), there is insufficient information and research on Applied Behavior Analysis based treatment for Autism Spectrum Disorder. Treatment providers are few and there is lack of policy & standards for licensing for ABA. (Kelly. M et al 2016)

The findings for this review have given me further impetus to inquire about the effect of ABA intervention that families have felt for their children in UAE.

2.03: The UAE context for Autism & ABA:

UAE is a 45 years old country that gained its wealth through oil exploration. It has a mixed population of UAE nationals and expatriates from all over the world. According to the UN (2015) estimates the UAE's total population was 9,157,000 as of mid-year 2015; immigrants make up almost 85% of the total population. This 85% of the expatriate population accesses education through a private school system where a variety of service providers compete to cater the diverse educational, cultural and religious needs of the students (Arif. M., & Gaad. E., 2008).

Life in UAE is fast paced and centered toward economic growth and competition. Although a compassionate and caring community, UAE may not be most conducive to meet the individual needs of a person with Autism. As mentioned in UAE' s Ministry of Education – Special Education Department released book - School for All (2010), formal School system was launched in UAE when it became a federation on December 2nd, 1971. UAE had provision for special education and service since 1979; much progress in the field is seen since 2006, after it adopted the United Nation's convention on Rights for Persons with disabilities.

Article 12 of the UAE Federal Law 29 of 2006 states,

“The country guarantees people with special needs equal opportunities in education within all educational, vocational training, adult education and continuing education institutions in regular classes or special classes with the availability of curriculum in sign language or Braille or and any other methods as appropriate.”

In 2009, The UAE signed the ratification of the UN Convention and in the following year the Ministry of Education, UAE in its document “School for All’ stated that,

“Each student is unique in his own way and needs to be provided with a safe, caring and stimulating environment to grow and mature emotionally, intellectually, physically and socially. Educators demonstrate a commitment to teach all students and provide them with a safe and supportive environment to develop to their maximum potential based on their individual strengths and challenges.”

As the need for services and intervention for children with Autism are very unique, it is important to have specific policy guidelines for education and treatment of children with ASD. At present, such policy or government led directives are missing in UAE.

UAE has a largely diverse population in terms of culture, ethnic origin, religion and language. The education system is to a large extent a profit driven private sector business. Although UAE has continually shown keen interest in provision of educational opportunities for persons with Special needs in creating a framework at federal policy level, the reality at implementation level is wanting of better practice & implementation.

The first step towards understanding and planning for autism services is the knowledge and information regarding its prevalence in the country. There is paucity in availability of this type of prevalence data. Valsamma. E., et al (2007), claim to the best of their knowledge that the study for prevalence of children with Pervasive Developmental Disorders in UAE may be the first of its kind in the Arabian gulf region. Unfortunately, there has been no further prevalence study for PDD/ASD in UAE; that is available in the public domain since. The prevalence data provided in their study is much lower compared to present rates for Autism Spectrum Disorder in the world. Similarly, Hussein. H., & Taha. G., (2013) have pointed out a lack of prevalence studies in the Arab region quoting lack of funding or lack of concern for research policies in Arab countries.

The awareness and acceptance of Autism is growing in UAE, but due to various social, cultural and religion biases, it is still considered a delicate subject to talk about and handled with a sense of pity and sometimes shame toward the person and their family rather than with a purpose to empower them. In UAE, this is witnessed from few recent newspaper articles as below: Hameli, A. (2015) writes in a newspaper article about initial denial of ASD for her son by a mother, she says;

“At first his mother refused to accept there was a problem. But soon after, she began to investigate and educate herself on the subject of autism.

“To be honest, I was ignorant about autism,” admits Mrs. Al Tunaiji, the mother of five.
“

Hameli, A., (2014) further explains the plight of another parent in UAE, “If only Arab society knew the daily challenge of parents with special needs,” says Mrs. Al Kaabi (mother of seven), who writes frequently on the subject of Autism for Al Khaleej newspaper. “If you can’t fully grasp my situation, at least, respect it.” Says, Mrs. Al Kaabi, while urging the people of UAE to understand the situation of parents like herself.

Similarly, Webster, N (2015) reports a parent’s statement that “The reaction in the community to these children has been really bad. There is a lot of misunderstanding. The problem is not with the children, but with society’s way of thinking towards them. Other autistic children struggle with most is the opportunity to be treated equally by society on a wider scale.”

In UAE, epidemiological data of prevalence of ASD is not available. There are no federal policy provisions for persons with ASD in the legislation; rather, it is included as a subcategory under persons with disabilities. There are various awareness initiatives started by government and non-government entities.

Autism was highly misunderstood and persons with Autism rejected until quite recently; this was largely due to lack of understanding, some socio-cultural impact on attitudes and lack of availability professionals in the field to educate the community about Autism Spectrum Disorders. This situation is seen changing gradually, with the advent of media, access to information through technology and increase in awareness of the disorder.

Writing this dissertation is driven by my personal experience in founding and running a support network for families and professionals touched by Autism since the last three and half years (Autism Support Network, Abu Dhabi). The numbers of inquiries we receive are increasing consistently and more and more inquiries are about treatment options. This study is hoped to go a long way in providing responses to parents, which will be based on objective data and research.

Just a cursory Internet search will provide many results of ABA practitioners in UAE, which seems like a double-edged sword. In the light of the need for service it is positive to see the growth of providers but in the absence of licensing and regulation, the quality and standard of service remains questionable. According to Kelly. M., et al (2016) review paper on Autism and ABA in GCC, there are at least 11 centres providing ABA

services within UAE. The quality and standards of this service is not verified in the review.

It is certain that there lies a unique gap between the need for ABA service and its availability in the absence of regulation. These factors make it all the more important to understand the perspectives of the parents with respect to the effectiveness of existing ABA services received for their child.

Chapter 3

METHODOLOGY:

3.01: Introduction:

Data was collected in two phases in order to investigate the parents' perspectives regarding the efficacy of ABA intervention for their child/children with ASD in UAE.

Phase 1:

General Overview of Parental Perspective:

An electronic/paper-based survey was made available to parents of children with Autism Spectrum Disorder in order to understand their perspective of the effect of ABA services for their child in UAE.

Phase 2:

Individual Parent Interviews were conducted in person to correlate the broad data received from the survey and to draw out specific themes regarding the positive and negative aspects of ABA services as per their point of view.

3.02: Research Phases:

Phase 1:

General Overview of Parental Perspectives:

An electronic and paper-based questionnaire was made available to parents of children with ASD in United Arab Emirates. (- Questionnaire). The distribution of the

questionnaire was done via local support networks, special needs centres, and therapy clinics; which were selected through an Internet search for Autism and ABA service providers in UAE. Prior to sending the questionnaire, it was piloted with 2 parents. Networks were requested by email and telephonic conversation to forward the questionnaire to their members and similarly centres and clinics were asked to do the same.

A total of 64 responses with filled questionnaires were received by email.

Keeping in mind the population in UAE, the questionnaire was designed in English and also made available in Arabic. (Appendix – Arabic Questionnaire).

The inclusion criteria for the questionnaire was:

1. Family resides in UAE.
2. Participant is parent of a child with ASD.
3. Child with ASD has received ABA intervention for at least 6 months.
4. Only one form is submitted per parent.

Although the criteria was specified in the communication with the special needs centres, clinics and support networks; there were some responses that did not meet criteria and therefore, were eliminated from the data set.

A total of 22 responses were eliminated due to following reasons:

3 were not parents of a child with Autism

17 had received ABA service for less than 6 months.

2 forms were submitted more than once.

The questions in the survey were formulated under three categories:

1. Information: About their self/Family/ training level/ type & amount of intervention/certification of service providers/ setting where service is provided. These questions had multiple-choice type of responses.
2. Parent perspective on the effect of ABA service for their child in various developmental domains such as communication, social interaction, language, academics, daily living skills, etc. The responses for these questions had to be selected from 5 choices, design as a Likert scale.
3. Parent perception of the effect of the ABA intervention on their family life. The responses for these questions had to be selected from 5 choices, design as a Likert scale.
4. Suggestions regarding needs for better intervention for their child in UAE. The responses for this question required a descriptive statement.

Responses were returned from the all seven emirates. (Abu Dhabi, Dubai, Fujairah, Sharjah & Um Al Quwain, Fujairah and Ajman). Unfortunately none of the responses from Fujairah and Ajman met the inclusion criteria.

Phase 2:

Personal Interview to understand Parent perspective on Effect of ABA Intervention for their child:

During Phase 1, an electronic and paper-based form was distributed, to the same parents, requesting for their interest & willingness to participate in an interview for phase 2. The distribution was also done through the Special Centres, Clinics and Support networks. 18 positive responses were received and 8 parents were selected. Selection criteria was based on:

1. Availability for interview within the time frame.
2. Signed information & consent form (Appendix) received.

18 Parents were invited for this interview as the second part of the study. Selected parents were sent an information and consent form. 8 parents who replied with a positive interest were selected for the interview. Interview appointments were set via telephonic conversations. 5 interviews were conducted in person and 3 were conducted via encrypted online conferencing program. All interviews were recorded with explicit permission from participants.

Having completed the e-questionnaire, it was clear that further investigation was needed to gain a more in-depth understanding of the perspectives of the parents. Interviews were non-structured to verify the findings from the questionnaire and also gain a more descriptive and personalized perspective from the parents.

Other than general information seeking questions, the rest were open ended, leaving room for descriptive responses and for the interviewer to probe for more information (Bell, J., 2016).

3.03: Data Storage:

First phase questionnaire responses were collected in the researcher's email account provided by the British University in Dubai (BUiD). They were systematically archived upon receipt. All data was collated in an excel sheet and stored on a USB with the researcher.

Paper-based Interviews were distributed to the clinics/centers/networks in sealed envelopes. There were no responses received to the paper-based interviews.

Phase two: Interviews were recorded on a voice recorder with permission of the participants. The recorded interviews were transcribed, typed and saved on a USB.

3.04: Data Analysis:

Phase1:

Survey Questionnaire Data was collated and summarized in an excel sheet using the Google form Data Summary tool. Each question was summarized and presented in a graphical form as an individual set with its own raw data. Some responses were then grouped in sets for a single graph for better visual representation of the data set. Descriptive answers were analyzed to look for emerging themes.

Phase 2:

Interview data was mainly qualitative in form. Data was analyzed in depth to look for themes. Each interview was analyzed and then each theme, across all interviews was analyzed to match the emerging themes.

This mixed method was chosen to understand the perspectives of parents. The interview was constructed to allow maximum freedom for parents to express their views, then, main themes that emerged from them were examined to match findings from the survey in the first phase.

3.05: Ethics:

Before undertaking this research study, an application to the university was made. Upon approval, an email / telephone contact was made with each center/clinic/network in order to introduce the purpose and assure confidentiality.

Confidentiality was assured to all identities.

In phase 1: Email responses were received in the Google form with no requirement of sender's email or other details.

In phase 2: Informed Consent forms were signed prior to interview and participants were assured of complete confidentiality of their and their child's identity. A number has replaced the name in interview transcripts for each parent and any names/statements that may disclose their identity have not been included in the statements in this study.

3.06: Limits & Challenges:

This research is limited in various ways:

1. By its size. The scale of the study is very small in comparison to the potential number of children affected by Autism in UAE. It was not possible to approach more participants due to barriers in distance & lack of resources.

2. ABA service providers are new and few in the country. Due to lack of licensing and policies for ABA services in the country, there is little availability; this makes the potential sample size quite small and concentrated in pockets.
3. Lack of spoken Arabic on my part was another limitation, as it was extremely difficult to arrange for an interpreter for more interviews. This limited the inclusion of parents who did not speak English.

The following challenges were encountered during this research study:

1. Cultural attitudes played a part in preventing parents from participating in the interview, as there is denial of the acceptance of the child's disability within the society.
2. Due to no availability of ABA services in two Emirates Fujairah & Ajman; there was no representation from those regions
3. Data Analysis was a challenge due to the fact that it had to be done by the researcher instead of including statistical data analysts. Thus, with the time constraints the researcher opted to present the survey in this way to show the emerging patterns indicating the perspectives of this group of parents included in the study.
4. Time-management was a challenge for me for a study of this nature. Due to my busy working schedule and multiple roles and responsibilities of my work, managing the time for this study was a challenge. Engaging in

this research taught me to about prioritizing my goals and working within realistic time frames.

5. Subjective bias due to my background in ABA and long- term service with children with ASD, was recognized & carefully avoided during the entire process. This was done continually by referring to the literature and triangulating the findings from the two phases with the literature that is available from prior research studies. This was a challenge and a learning experience.

It was a very interesting learning experience, conducting such a study after having been in the field in UAE for almost 15 years. I learned that (a) no matter what I understand as effective intervention, it is ONLY effective when it makes a positive difference in the lives of the person with ASD and their immediate family. (b) Including and empowering parents is the most effective way for ASD, but it is extremely difficult for parents to overcome their emotional barriers to take responsibility to provide their child's intervention. (c) As a professional, the way we interact with parents regarding their child is of utmost importance. Professional behavior must be coupled with compassion. This is a long journey for parents and professionals and both need to see the other's perspective in order to build a fruitful relationship.

Chapter 4:

RESULTS:

Phase 1: General Report of parental Perspective on the effect of ABA intervention for their child with ASD via survey questionnaire.

Summary interpretation of Data:

64 parents from Abu Dhabi, Dubai, Ras Al Khaimah, Ajman, Fujairah, Um Al Quwain & Sharjah responded with their answers to the electronic form. Out of which, 22 responses did not meet the inclusion criteria, thus they were removed from the data set.

I am not aware of how many parents were sent the electronic form as it was distributed through schools/centres and support networks.

A summary of the data per question is given in this chapter followed by an overall summary per theme.

In the survey questionnaire form, the questions have been clustered by themes.

Questions 1 to 4 are about general information of the child with ASD such as age range, gender & level of diagnosis. It is clear from this data that it matches the worldwide statistics in regards to the ratio of its occurrence in males versus females. Out of the 42 participants we have 83.3% males and 16.7% females. (ref ratio data). A large part of the participants have reported that their child has either moderate (45.2%) or mild (26.2%) level of impact of ASD and there is a considerable number of parents (26.2%) who do not know the level of impact for their child.

Question 1:

Are you a parent of a child with diagnoses of Autism Spectrum Disorder living in UAE?

100% - All 42 parents responded YES.

Question 2:

Your child's age is:

Age Range of the Children

Age Range	Number of Children
2 to 5 Years	20
6 to 10 Years	12
11 to 15 Years	9
16 Years & above	1

Table 1: Age Range of children of the survey participants.

Question 3:

Your child's gender is:

Male – 83.3%

Female 16.7%

Question 4:

Your Child's level of diagnosis is

26.2% - Not sure

26.2% - Mild

45.2% - Moderate

2.4% - Severe

Level of ASD Diagnoses of the children - Number

Level of Diagnoses	Number of Children
Not Sure	11
Mild	11
Moderate	19
Severe	1

Table 2: Number of children in per level of diagnosis

Second Cluster of questions numbers 5 to10 are about the duration of ABA intervention received and type of certification of team members. Results suggest that half of the participants' children have been receiving ABA intervention for more than 2 years. This gives strong validity to the responses they have given, as they are from a rich experience of a substantial duration of intervention.

Question 5:

How long has your child been receiving ABA intervention?

7 to 12 months – 21.4%

13 to 23 months – 28.6%

24 months or more – 50%

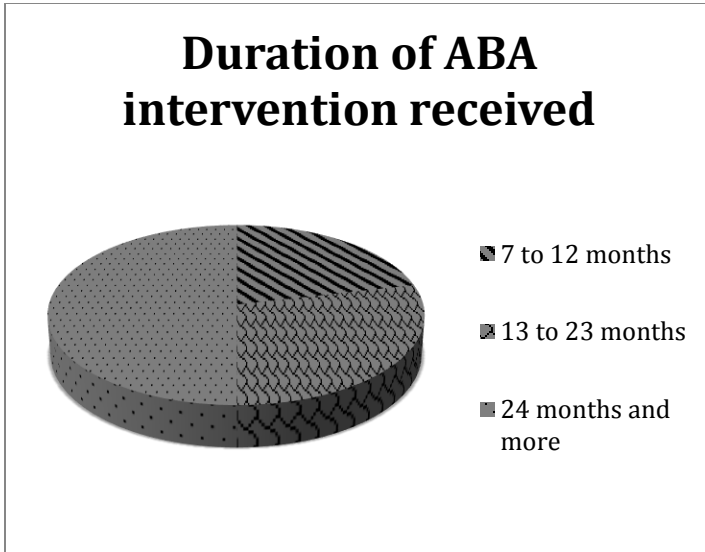


Figure 1: Duration of time ABA intervention received

Question 6:

How many hours per week does your child receive ABA intervention?

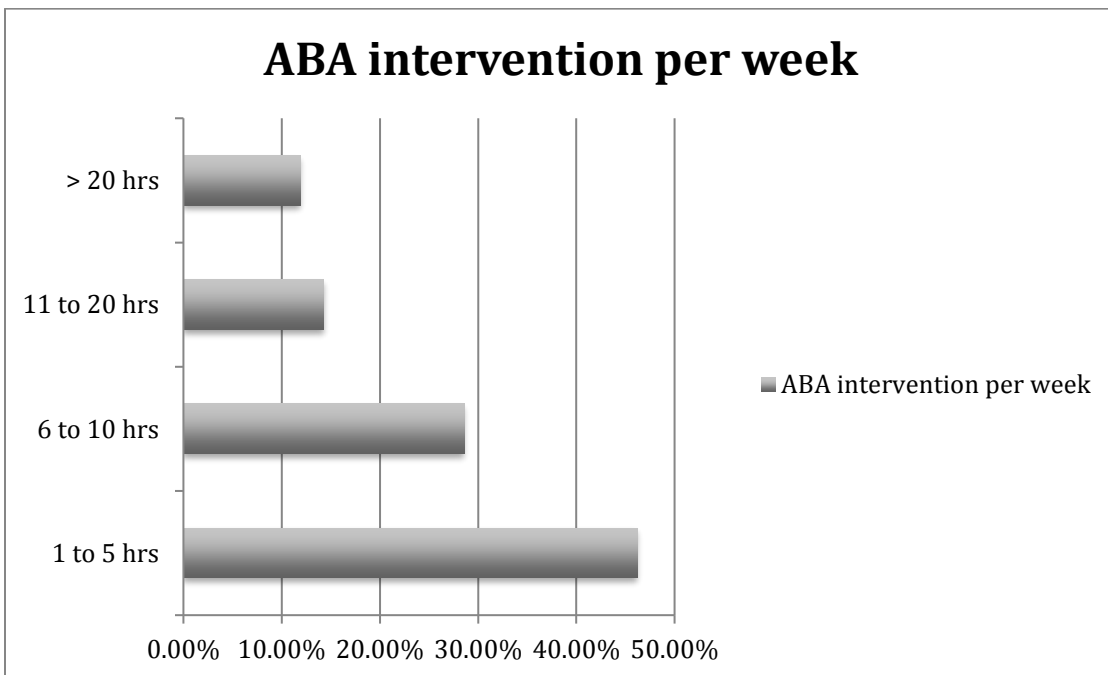


Figure 2: Weekly amount of time of ABA intervention

Question 7:

What is the level of certification of your child's ABA program supervisor?

BCBA – 33.3%

BCaBA – 31%

RBT – 4.8%

No certification – 31%

Question 8:

What is the level of Board Certification of child's therapist?

BCBA – 13.3%

BCaBA - 26.2%

RBT – 21.4%

No certification – 38.1%

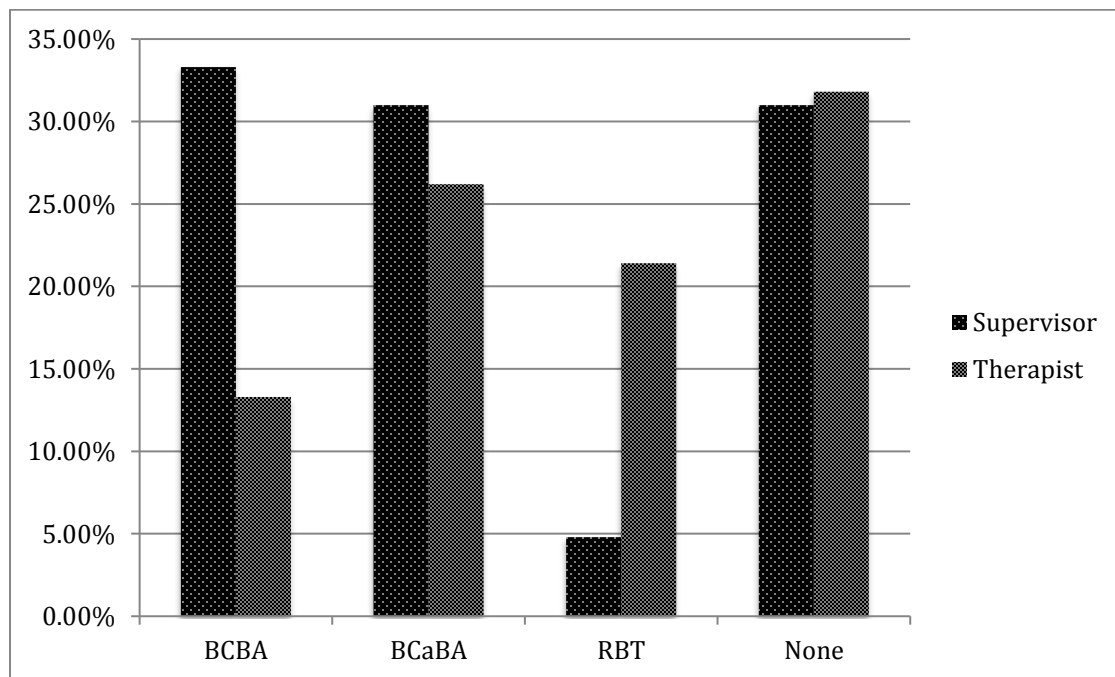


Figure 3: Level of certification of Supervisors and ABA therapists

Question 9:

What is the setting for ABA intervention?

Home – 33.3%

School – 7.1%

Special Center – 31.3%

Combination of both – 28.6%

Question 10:

How many members are there in your child's ABA intervention team?

4 or more – 10

3 persons – 7

2 persons- 14

1 person – 11

Questions 11 & 12 refer to the level of training and amount of time spent by the parent with their child at home implementing ABA intervention. Here it is seen that only 11.9% of the parents have indicated that they do not spend any time implementing ABA intervention with their child. Rest of the parents; have reported that they spend anything between 1 to more than 10 hours implementing ABA with their child. (refer in discussion)

Question 11:

What is your level of ABA training?

None – 16.7%

Reading books and Internet – 33.3%

Attended workshops & Lectures - 45.2%

Taken Courses at University Level – 4.8%

Question 12:

How much time do you spend per week with your child implementing ABA intervention?

None – 11.9%

1 to 5 hours – 52.5%

6 to 10 hours – 21.4%

More than 10 hours – 14.3%

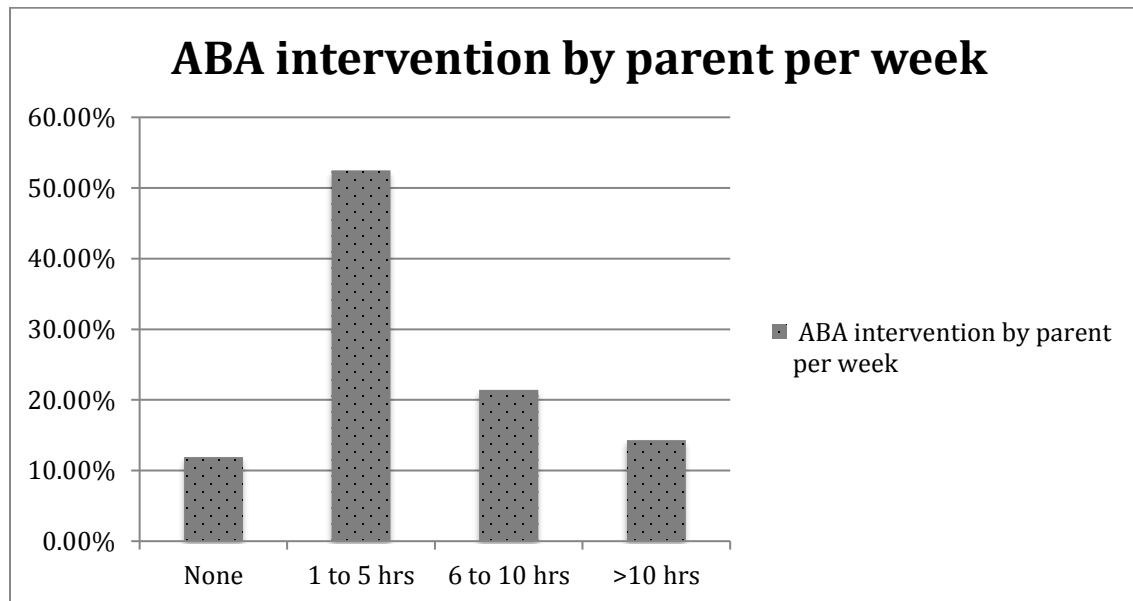


Figure 4: Amount of time spent on ABA intervention by parent with child per week

Question 13 directly asks the parents response about their degree of agreement/disagreement to the positive impact of ABA intervention for their child with ASD. Result is in favor of agreement (Agree 73.8% Strongly Agree – 19%) and a smaller number of responses were neutral ((Neither Agree Nor Disagree – 7.1%).

It is important to note that none of the parents indicated disagreement to this question.

Question 13:

ABA intervention is making a positive change in my child's development.

Strongly Disagree – 0%

Disagree – 0%

Neither Agree Nor Disagree – 7.1%

Agree 73.8%

Strongly Agree – 19%

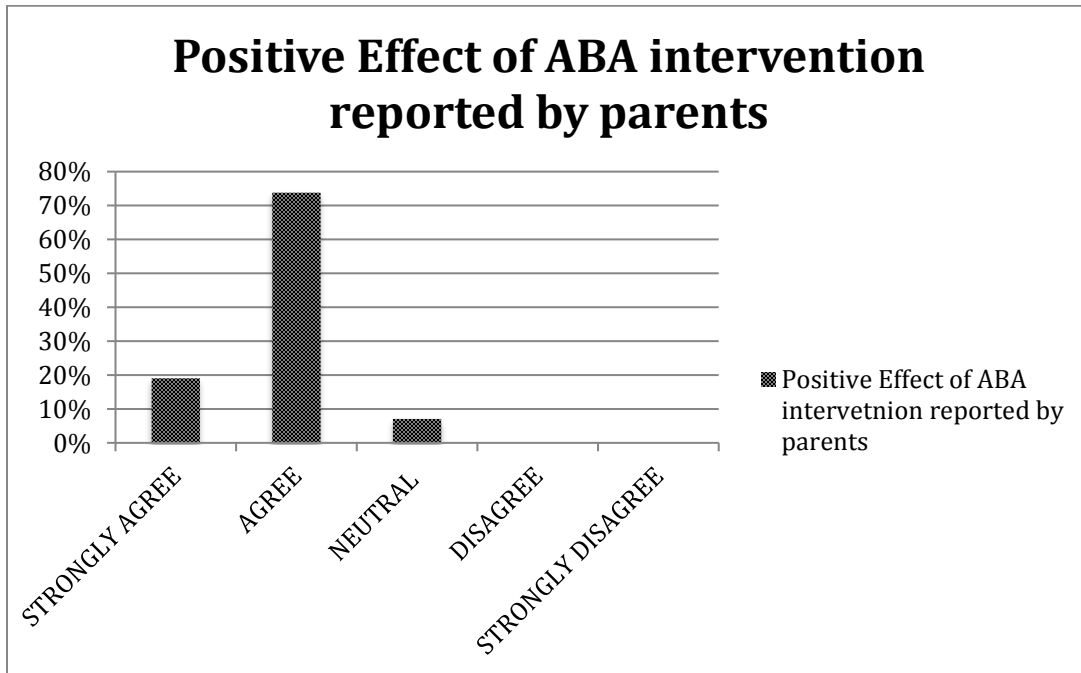


Figure 5: Parents’ response to effectiveness of ABA intervention.

Cluster of question 14 to 20 are specifically targeted to look for parent's perspectives in the positive impact of ABA intervention in specific skill domains such as communication, self care, language, fine motor, gross motor, academic and social interaction skills.

Question 14:

Since the ABA intervention, I have seen development in his/her communication skills

Strongly Disagree – 2.4%

Disagree – 2.4%

Neither Agree Nor Disagree – 11.9%

Agree – 59.5%

Strongly Agree – 23.8%

Question 15:

Since the ABA intervention, I have seen development in his/her self care skills

Strongly Disagree – 0%

Disagree – 7.1%

Neither Agree Nor Disagree – 14.3%

Agree – 59.5%

Strongly Agree – 19%

Question 16:

Since the ABA intervention, I have seen development in his/her Language skills

Strongly Disagree – 0%

Disagree – 11.9%

Neither Agree Nor Disagree – 21.4%

Agree – 47.6%

Strongly Agree – 19%

Question 17:

Since the ABA intervention, I have seen development in his/her Fine Motor skills

Strongly Disagree – 0%

Disagree – 2.4%

Neither Agree Nor Disagree – 21.4%

Agree – 59.5%

Strongly Agree – 16.7%

Question 18:

Since the ABA intervention, I have seen development in his/her Gross Motor skills

Strongly Disagree – 0%

Disagree – 0%

Neither Agree Nor Disagree – 33.3%

Agree – 54.8%

Strongly Agree – 11.9%

Question 19:

Since the ABA intervention, I have seen development in his/her Academic skills

Strongly Disagree – 0%

Disagree – 0%

Neither Agree Nor Disagree – 26.2%

Agree – 59.5%

Strongly Agree – 14.3%

Question 20:

Since the ABA intervention, I have seen development in his/her Social Interaction.

Strongly Disagree – 0%

Disagree – 4.8%

Neither Agree Nor Disagree – 26.2%

Agree – 54.8%

Strongly Agree – 14.3%

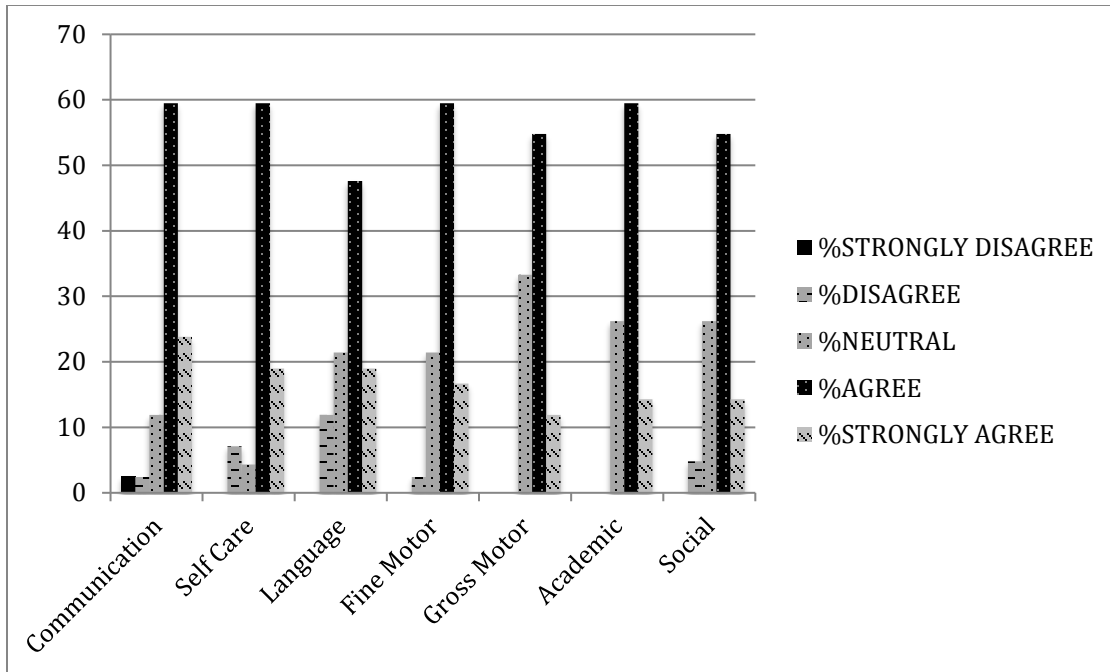


Figure 6: % of Parents response for development of their child, across skill domains

Questions 21 – 24 are seeking to investigate the impact of the intervention on the quality of the child’s family’s life with regard. This aggregate result shows:

Question 21:

ABA intervention has made a positive impact on the quality of our family's life.

Strongly Disagree – 2.4%

Disagree – 4.8%

Neither Agree Nor Disagree – 16.7%

Agree – 61.9%

Strongly Agree – 14.3%

Question 22:

ABA intervention has made a positive impact on the quality of my life as a parent.

Strongly Disagree – 0%

Disagree – 7.1%

Neither Agree Nor Disagree – 11.9%

Agree – 61.9%

Strongly Agree – 19%

Question 23:

My other children find it easier now to be around my child with ASD.

Strongly Disagree – 0%

Disagree – 4.8%

Neither Agree Nor Disagree – 59.5%

Agree – 19%

Strongly Agree – 16.7%

Question 24:

It is easier for us to go out together as a family.

Strongly Disagree – 0%

Disagree – 0%

Neither Agree Nor Disagree – 31%

Agree – 50%

Strongly Agree – 19%

Question 25:

I feel more hopeful for my child's future

Strongly Disagree – 0%

Disagree – 2.4%

Neither Agree Nor Disagree – 21.4%

Agree – 54.8%

Strongly Agree – 21.4%

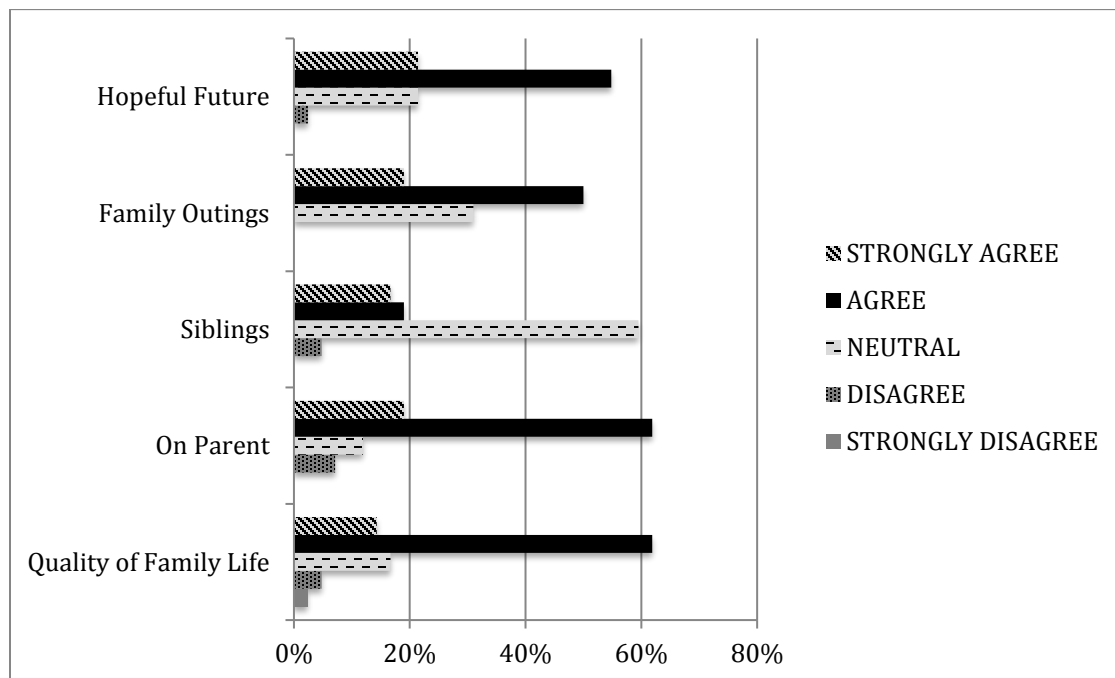


Figure 7: % of Parents' response to domains that impact their family life

Questions 26-28 are aimed to understand the level confidence the parent feels in implementing the ABA interventions himself/herself with the child and the level of access they have to an ABA practitioner.

Question 26:

I am more confident when teaching my child any new skills.

Strongly Disagree – 0%

Disagree – 7.1%

Neither Agree Nor Disagree – 19%

Agree – 61.9%

Strongly Agree – 11.9%

Question 27:

I feel more comfortable when practicing the skills that he learns during ABA intervention.

Strongly Disagree – 0%

Disagree – 4.8%

Neither Agree Nor Disagree – 28.6%

Agree – 45.2%

Strongly Agree – 21.4%

Question 28:

I have easy access to the ABA therapist/supervisor for advice.

Strongly Disagree – 2.4%

Disagree – 4.8%

Neither Agree Nor Disagree – 19%

Agree – 50%

Strongly Agree – 23.8%

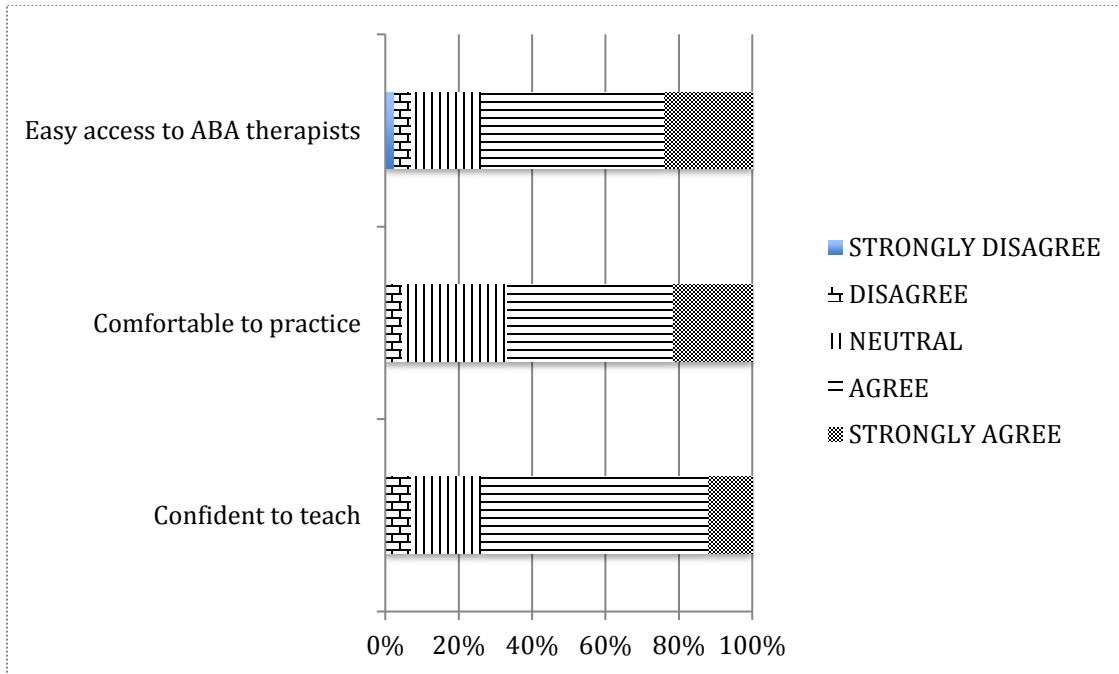


Figure 8: Parents' level of comfort with access to ABA professionals

Question 29-30 & 31 refer to future directions with regard to parent training, increasing ABA intervention hours and descriptive suggestions to improve the effect of ABA intervention for their child.

Question 29:

In order to improve the effect of the ABA program for my child, I would recommend more parent training in ABA.

Strongly Disagree – 2.4%

Disagree – 4.8%

Neither Agree Nor Disagree – 19%

Agree – 50%

Strongly Agree – 23.8%

Question 30:

In order to improve the effect of the ABA program for my child, I would prefer more hours of ABA intervention for my child.

Strongly Disagree –

Disagree – 7.1%

Neither Agree Nor Disagree – 14.3%

Agree – 50%

Strongly Agree – 28.6%

Question 31:

I would also like to recommend the following in order to improve the effect of the ABA program for my child.

36 responses were received for this question.

Recommendations for improvement in the effect of ABA service – By parents	Responses
Parent Training & Involvement	6
More Hours of ABA intervention	5
ABA training for school staff (teacher & Para-professionals)	5
Add other therapies such as Occupational Therapy, Speech Therapy	3
Make ABA intervention more affordable	2
Make access easier	2

Table 3: Parent suggestions for improving the effect of ABA intervention.

These were the main points that emerged from the responses collected for question 31:
Parent Recommendations to improve the effect of ABA intervention for their child

Phase 2:

Interview: Parent's report on the efficacy of ABA intervention for their child with ASD. It was designed like a guided/focus interview. This kind of design allows the participant to talk freely about what is of importance to them rather than to the interviewer, yet a loose structure is kept in order to cover all topics that may have been identified as crucial to the study. (Bell. J., 2006)

A verbal explanation and opportunity to ask questions regarding the study was provided to each participant. Few initial questions regarding the family and child were asked in order to break ice. Interviews were recorded, as prior permission in the information and consent form had been obtained.

The interview was formed to give the participants an opportunity to speak about the following themes:

1. General information about them & their child's ABA intervention. (location, duration & length of intervention)
2. Their journey to ABA for their child – their knowledge about it, the barriers, expectations, training

3. Impact of ABA intervention on them, their child and their family.
4. Their recommendations for improving ABA service for better effect for their child & for UAE.

The interviews were conducted in person or over an Internet meeting application (zoom.us). All interviews were recorded and transcribed there after.

8 interviews were conducted – 2 each from Abu Dhabi, Dubai & Sharjah, one from Ras Al Khaimah and 1 from Um al Quwain. These included parents from various ethnic and national backgrounds. This was especially done in order to gain a fair representation of members of the multicultural society that UAE is made up of.

Theme 1:

General Information: All parents reported that they lived in UAE, had at least one child with a diagnosis of Autism Spectrum Disorder who was receiving ABA intervention for at least 6 months. Parents included in the study were from Sharjah, Dubai, Ras Al Khaimah, Um al Quwain and Abu Dhabi. The ethnic backgrounds of the families varied to represent the varied population of UAE.

Theme 2:

Their Journey to ABA for their child with ASD:

It was seen that many parents felt powerless during the daunting decision making process for treatment for their child. Willing to do whatever it takes, most seem to be dependent on professionals for advice.

Parent 1:

[w]hen we came here we tried to put him in normal school but it was so hard, so one of the teacher told us about this Center (ABA). She said go there and I am sure he need that. Because we thought that if he goes to normal school he might be better and better. We don't have any choice we do that or otherwise keep him at home. We will not stay for him all the time he has to progress he has to become normal.... For me he become like a normal kid, normal person talking asking and taking care by himself that's all.

Parent 2:

[S]he was doing speech therapy and occupational therapy and also the academic this is something new to her the call it as VB they call it(...) but they (center)suggested that she needs (ABA). They know better than us.”

Parent 3:

[T]he first professional that I met explained to me what is ABA and explained to me the benefit of the environment. When I first started it was even hard to find all the Centres and they were supposed to come to the house for the arrangement (...)That was only six hours a week. And there was no Arabic speaking therapist and even she cannot do it at home and transfer all the conversation to English. Especially the mother tongue language the emotion was missing. We didn't see much result of changes so we changed to another Center. Maybe I was rushed because I gave each Centre about 6 months' chance.

(...)my ultimate hope was she is delayed and bridge the gap between her journey and the other children.

Parent 4:

[W]e didn't know. We knew something is wrong with the child(...) school advice to join ABA(...) Finding service other than recommendation is very difficult(...)to get him to the level to the normal school.

Parent 5:

[A]s a parent, I was ready to go through anything... It is difficult actually because everybody sitting having a signboard and say I am speech therapist or we do help. ...the right therapy I am not sure when it is started. First it was a lady alone he was working with. She used to do with him everything. From there we moved him to a nursery kind of place there also they had different things but you know the improvement was not there. Then we moved into one lady alone. She said she is a speech therapist. There was improvement but that was not moving.

Parent 6:

[A]ctually, when you are looking for a therapist for your child you go thru a lot of research and a lot of bad people. You meet a lot of bad people. You meet lot of medications. People who are willing to give you medication which may not work, people who are going to give you weird kind of medication. And there are

people who claim to be therapist and are not good so you go through a lot. Then you actually settle down on a person you are more comfortable with and you feel is the most honest. Then you reach one point. It's not about ABA because you will get ABA very soon. Getting the right person who is giving out the right ABA. There are ABA people in the field but they are not doing justice. They are out to make money. Just a money-making thing for them, it's not that simple.

Parent 7:

[I] contacted BCABA in India and got her to come to Ahmedabad where I used to live. She did the parent training for some of us. I tried to apply those principals at home with my son, who was 4 at that time and I immediately found that he was able to respond.... And that is where I realized that ABA might help him and then the whole journey began of finding a ABA.

Parent 8:

[T]here was not lot of choice sincerely they was almost nothing... and the process at that point of time was not so much choosing it was just being able to secure the services because they was not a huge of a choice. it was a bit difficult because he did not have a formal diagnosis for autism.(...)and then I had to go back and go through a formal diagnosis process, which at that time I also didn't feel was very useful. It is a matter of just filling out paper work but not really getting a lot of information from the doctors. So, that was hard and it was a lot of waiting. In his case, we pulled strings to get him in quicker, which I think was a

right decision. We've never done that before. He started when he was about 3 and a half. Honestly was under 6 months probably when we started trying securing his position which is very fortunate. Specially at that time.

Theme 3:

ABA Training for parents:

Training themselves in ABA was not seen as an important aspect by most parents. This could be due to lack of availability of professional training and burnout on the part of parents in dealing with their child.

Parent 1

“No, we tried just to care about him but not specially to work.”

Parent 2:

“No”

Parent 3:

“(…)have tried a session some at home basic things but nothing like ongoing training.”

Parent 4:

“Training as such no. Ok consulting each other and trying to get advice. But special training didn't.”

Parent 5:

[I] didn't go for any. It's getting tense by taking up of computer reading thru things although we have knowledge in it as you know digging in more. So, I thought let's be a mother who does not know anything.

Parent 6:

"No I didn't take any formal ABA training it's like you can learn cooking while watching so informally yes..."

Parent 7:

"I have attended the parents training at various institute centers that my son went or in school he had any ABA but nothing formal which will involve a certification."

Parent 8:

"Well just parent training. Through various parent trainings through the centre some of which(...) I did complete the fundamental parent training for mothers."

Theme 4:

Impact of ABA:

All parents in the interview reported a positive impact at varied levels and domains.

Parent 1:

“Yes, he is more wise and he is focusing better because when we start he was another kid and now he is here its such difference... He is more quiet.”

Parent 2:

“She is improving a lot actually, yes with the speech she is speaking a lot and also with the academic, big improvement, able to communicate even more better, listens a lot more, behavior has improved a lot.”

Parent 3: (Live interpretation from Arabic recorded & transcript)

‘(...)At first I didn’t see any result even small results. “She says”, how much we paid and the results we saw were not proportionate. “She says” we paid up to 20,000 Dhs a month(...) We have seen a lot of changes(...) I am not sure what’s natural progression because she is growing up and what is ABA. (...) it’s very hard for me to differentiate. (...) for example she joined ABA for a period of time but I didn’t see much changes but with her growth she got more attention and more concentration that was necessary during the specific period of time during the ABA(...) I have seen a general sense(...) ABA is better than anything else’

Parent 4:

[P]ositive all of it(...) very much! Now he understands. First year what made me really surprised.. His birthday when I brought the cake he was jumping open the cake, open the cake. But this time for his birthday when I brought the cake he

was calm. He is not trying to open. This kind of small small things really made big. Now he understands. He broke his leg twice. He was running he never felt the scare that something is wrong, he could not even go down the stairs proper. Now he can go run stairs and these kind of things. There is less fear if we are going out(...) his interaction with people was always open but now he is questioning more whether to contact or not(...) it's easier for us(...)

Parent 5:

“There is a lot of improvement. We do see signs of it(...) A positive. Definitely a positive(...) Following instruction exactly(...) two instruction also he follow(...) We are not worried he will walk towards the road.”

Parent 6:

[S]he is a changed person today she talks a lot(...) She is more friendly. Yes, definitely there is a positive change in her life. She has gained better in the therapy that she went through. Speech especially. She had speech delay. Speech has grown. Her reading has grown. Her ability to interact has grown. She has also learned a lot of things, which children at her age don't learn because she was doing other things(...) She has learned in a nice way in a fun manner through games. So, she learned a lot.”

“Life becomes easier. You know that life becomes so much more easier, happier earlier we use to be scared just going out, how will she behave? how would she be? But things changed over a period of time. Life becomes normal. It's no

longer stressing about everything like how we will go out, how will she be how will we manage to eat everything becomes normal you can do it you know how to do it. If you are not doing it then okay this is. You just don't over react over your child. It's just a child and you need to deal with it differently. I guess you learn that by watching.

Parent 7:

[H]e was verbal previously he had become non-verbal. And at four and a half the minute he started ABA he started intra-verbal which helped him to sing rhymes, use it functionally like asking for water, going to the toilet Absolutely Positive(...) Getting him to eat his food, getting him to wear his clothes, getting him to may be do a worksheet. Getting him to come to doing non-preferred activities(...) Those kinds of things, which are so important, positively yes. Because including my son we are 4 in the family. So even my husband and father-in-law have learnt how to apply those kinds of principals. Do this and I will give you this. Its life easier for all of us.

Parent 8:

[I]t's hard to really think back how unskilled he was. But he really was. So, all of that you see now is shaped with ABA which I think is probably the most dramatic impacts with every action he has with people and now he is very skilled. (...) his issue is he doesn't understand why he has to do things that people ask from him. Or they might not fit in his schedule. So that is where we

have used ABA, not academically or really teaching him actual concept because he is better than the usual case there. He kind of catches on very well. But performing academically absolutely has been shaped and is still in the process of being shaped.

Theme 5:

Would they prefer more ABA for their child?

There were mixed responses in this theme. 6 parents opted for more ABA if possible and 2 parents were satisfied with the amount of ABA their child was receiving.

Parent 1:

“If that help him; for me it’s no limit.”

Parent 2:

“Yeah Why not! Something that will benefit her to help her.... like how to deal with the child in the house.”

Parent 3:

“ If prices will be less we can give them more (ABA)”

Parent 4:

“We would love. If this would have possible yes then we would also have not reduced.”

Parent 5:

“No at present.”

Parent 6:

“No it was something we thought about. We took a lot of therapies initially more hours and then we reduced it.”

Parent 7:

“Oh, yes although I feel sometimes that he has outgrown it but yes, I mean I would say 50-50 at this age. At younger age, definitely I would suggest ABA for starting out parents but around 8 or so I would say 50 – 50.”

Parent 8:

[Y]es since Inclusion(...) there is much less direct one on one. I honestly like the transition model better where there is balance of the pullout one on one and sort of specialized classrooms and the inclusive classrooms but unfortunately in this country it's not its sort of government school and the implementation because of that, this is not ideal for him and because of his academic level begin quite high he can be challenged in an environment. I do that is my idea for him, we could still have the dedicated time in the day to really have more one on one ABA I think there are lot of places where we need that time. That is very very hard for me to affect change at home and it is very very hard for his teacher to affect

change during a school day in academically bigger school as well. It's very hard. In that way, it's not that he is not receiving hours of ABA but I wish that we could have in a transition model rather than the full inclusion.

Theme 6:

Barriers to ABA intervention:

Some of the barriers identified in the interviews were :

Cost of treatment, fear of allowing child to be with therapist, discomfort in accepting the need for therapy, finding the right place from the perspective of location and quality of service, lack of services, lack of transparency and unprofessional attitude of service providers and lack of acceptance from family members and lack of policy and standards for service providers in UAE.

Parent 1:

“But this is really expensive here; it's really expensive it's not only third party but I don't know why. Treatment here in UAE it's unbelievable

Parent 2:

“None”

Parent 3:

[F]ear was my biggest(...) especially she worked alone with my daughter. She is young something might happen to her. I was just watching just to make sure as

she was little(...)ABA its does not seem to be regulated it is different(...) from the Centre to Center(...) I don't know that the way ABA is or it is the individual (center).

Parent 4:

[U]ncomfortable is always like this that you think about that you have a handicapped or kid with disabilities(...)to recognize that there is something wrong it takes time you always say its normal but then up to a certain point when you say normal(...) then we have to do something to help him.

Parent 5:

[G]et the right place, commuting and the price, the charges everything. It's a difficult decision actually. Because they don't explain. These are not things that are easily available. People still have problem talking about it or explaining.

Parent 6:

This parent spoke about barriers and recommendations jointly so they have been recorded under the recommendations Theme.

Parent 7:

"(...)yes everyone in Dubai was aware of ABA. My experience was very good because my son started getting ABA when he was four and a half."

Parent 8:

[N]obody (in the family) wanted to start ABA services except me. Because even at the time he spoke and he would make eye contact with people he would respond to some people at time I even had one well respected psychiatrist who said “oh no, no he is not autistic because he just looked at me”. He was one of those kids that at a very young age you could say I heard “he is just a boy. You make a big deal out of this. You got to cause a problem”. No nobody was. Nobody knew what ABA was they were not against ABA but they were just against any sort of special education or special support.

(...)it was just being able to secure the services because there was not much of a choice.

To go through a formal diagnosis process just filling out paper work but not really getting a lot of information from the doctors. So, that was hard and it was a lot of waiting.

(To secure services) we pulled strings to get him in quicker, which I think was a right decision. We’ve never done that before.

Theme 7:

Parent’s recommendation for better effect of ABA for their child & in UAE:

Parents recommended honest & transparent professional attitude towards them by the service providers, professional collaboration, cheaper services, improved availability of

professionals, awareness about ABA, increased social activities for children, increase accessibility for all families by including it through insurance provision and add transition model for better inclusion into schools.

Parent 1:

“Collaborated because every child is one type and every child needs good care for this (they) are very special.”

Parent 2:

“Am very happy.”

Parent 3:

“Prices will be less so that we can give them more
(...)everything into the same session not necessary to make it into speech.”

Parent 4:

[T]o improve the availability of specialist(...) to request some support, Some society, some kind of activity for those kinds of kids say once per week. To do something together like team building, painting that would help us.

Parent 5:

[T]he knowledge of it what is ABA? What is ABA? people do not know what is ABA? It's just a technic or something nobody knows. The knowledge of it has to

be more(...) People need to know more about it(...) awareness a lot of awareness.

All that he learns has to come home(...) wherever we go in his normal environment.

Parent 6:

[I]t has to be multipronged actually, there are lot of people who come down to Dubai with lot of qualifications, But, they are downright bad when it comes to even talking to the parents. First be honest in their approach and secondly be kind to the parents. Parent who comes there goes through a lot of problem, is going through lot of problem emotionally and is also faced a lot of adverse feeling from society. They don't need therapists who are sitting there with machine guns. Shooting violently at them with their speech.

Thirdly, their charges are very high most of the time. So, it is not within the reach of many people who have problem with their children and can't afford it, and their children just stay at home waiting for school if they can get in special need school which are there few. So, the children are really suffering.

The fourth thing is there has to be more openness in the kind of system, which is setup. The communication has to be open it has to be recorded. ABA says everything is to be recorded. But not everything gets recorded. Even if it gets recorded it is not open for the parents to see so that has to be there. Shutting a child in a room and saying he is undergoing a therapy and you not seeing anything is not a way.

Fifth, Insurance should also provide for having these things in them. That few hours or certain number of hours if the child is diagnosed with the problem insurance company should be covering those. These are few of them.

Parent 7:

[L]ess table top more of environmental teaching, more fun sometimes I find it very I don't want to use the word because it is so commonly used. "Dog training". I would like it to be more fun and less rigid.

I am tired of people saying I am a ABA therapist. No qualification no nothing and I am a ABA therapist. There got be some sought of a regulation like RBT is great I don't know if there are exams which sort of see whether the therapist is able to maintain and enhance their learning. I think there should be some sort of regulation in the UAE for that.

Parent 8:

For child:

[T]o integrate(...) keep a little more of the structure within the inclusion program. (Since Inclusion in Mainstream school started).. there is no more home visits, you are on your own. The families may not be ready to the point. There is so much focus when your child first start there is so much focus on helping parents understand how to do these basic things, how you can make a schedule at home and how you can implement consequences. And then if when your child develops at a certain point you can deal with him normally, which you cannot.

Or if we have gained enough information to take him to the next level on our own which is also not the case(...) there is no support there for the parents to deal with those problems they are having.

For UAE:

[G]et ABA services in UAE. I mean that there are so many families that I met where based on their nationality, based on their income, based on their child's age, based on their child's challenges they don't fit into the little box. That's a narrow box(...) I know a lot of families that cannot finance that are on the income bracket that cannot afford that. Insurance does not cover anything I think there is not a system where it is applied and available across the community.

Chapter 5

5.0 DISCUSSION:

UAE is a country with a population from various ethnic & cultural backgrounds. Even with those differences, the responses to the parents' situation of having a child with ASD and procuring ABA services were similar.

Looking at the main research question:

1. Do parents report that there is a positive effect of ABA intervention for their child and family?

What is the overall experience of the parents in procuring and using ABA intervention for their child?

Over all it was seen that ALL parents in the interview and 95% parents in the survey have agreed to the positive impact of ABA intervention, at varied extents, for their child. 5% parents responded neutral in the survey to the question regarding positive impact of ABA. There were no responses in disagreement.

There was strong agreement in the skill domains where they saw improvement. Many parents saw improvement in their child's participation, instruction following, fine & gross motor skills, daily living skills, social & academic skills and some in language & communication skills. This was seen both in the survey & interviews.

How does a parent describe positive effect of intervention for their child and family?

The most socially significant impact described by parents in the interview and survey was a better quality of life. Noteworthy are the descriptive statements such as “life becomes easier”, “we have less fear to go out”, “he stays calm for his birthday party, small things that change are very important for us”.

62% of surveyed parents agreed that the quality of their family life had improved and 19% strongly agreed to the same.

In another parent evaluation study about ABA intervention in Northern Ireland, parents reported that ABA had a positive impact on the family, giving it more structure and making it possible to go out on more family outings (Dillenburger. K., et al 2002)

Parents described their child’s positive development in communication, language development, self-help, academic, daily living, gross and fine motor skills in the interview. The same is evident also in the survey questionnaire.

What do parents see as barriers in the effectiveness of ABA intervention?

The two barriers that a high percentage of parents referred to were the cost of ABA services and the lack of standardization of services. As the costs of ABA intervention is extremely high many parents either forego the service or they compromise with lesser hours or non-certified providers that are cheaper. This impacts the affect for the client and also misrepresents affect of ABA intervention. UAE comprises of more than 80% expatriate population that must access health and education services privately. Insurance providers do not yet cover the cost of ABA intervention and thus the entire burden falls

on the family. ABA, by design is an intervention that requires a high number of service hours, making it even more expensive to maintain.

Many parents from the survey and interview set were seen as not aware about ABA; but they were seeking the intervention based on recommendation from educators or clinicians. This highlights the lack of their knowledge as a consumer, thus making them vulnerable to the professionals in the field. It is therefore, important to point out that due to its variety of service styles and providers, ABA leaves families to the mercy of the honesty and integrity of the practitioner. Some parents complained about the attitudes of the professionals while searching for service providers. The Behavior Analyst Certification Board (2016) has a prescribed professional and ethical compliance code for practitioners, but there is a lack of guidelines for the consumers about what they should expect.

Secondly as seen in the interview and survey, many parents do not seem to be aware of professional credential and certification for ABA practitioners, thus they are at risk of being cheated by non-certified personnel.

Some parents also found it difficult to procure services. They spoke about lack of access to information and availability of service providers. There were also concerns about transparency and attitudes of ABA professionals towards them. One mother stated “The communication has to be open it has to be recorded. ABA says everything is to be recorded. But not everything gets recorded. Even if it gets recorded it is not open for the

parents to see so that has to be there. Shutting a child in a room and saying he is undergoing a therapy and you not seeing anything is not a way.”

Although as seen from the data in this study, ABA seems to have a positive impact on some children and their families, there still remain those who do not experience the positive impact. Further investigation in the future is needed to find out what can be done in order to change the extent of the positive impact for more families?

Are there unified standards for consumers of ABA in order to evaluate the adequacy of the ABA programs provided? The larger question here is not only in UAE but pointing worldwide to the field of ABA where it seems the practitioners do not have a consensus about what constitutes the best ABA program for the learners in question.

Having a child with ASD, which in itself is extremely puzzling and then having to navigate through a maze of service provision without any leads for standard practice is like looking for a needle in a haystack. The least that can be done for the parents is to increase awareness about ABA and provide a policy framework for best practice. As in every other profession, over time, the best practice shall prevail by virtue of consequences.

Chapter 6

CONCLUSION & RECOMMENDATIONS:

In conclusion, it is evident from this study that many families have experienced positive impact of ABA for their child with ASD. There are still many barriers related to awareness, availability and policies for ABA in UAE.

In order to have better impact that reaches more families, the following recommendations are made:

1. ASD prevalence studies to be conducted and data made available for public access, in order to understand and plan for the need for services.
2. Encourage research at all levels and gather as much relevant data as possible. Further research in specific intervention models and long-term follow up studies to understand and compare effectiveness of interventions is recommended.
3. Federal authority to recognize ASD as a spectrum disorder, due to which each individual's need for service is varied. Authorities from the Health, Education and Social care sector need to collaborate to create an environment of support, and evidence based intervention options. This is a mammoth task and due to the nature of the mix of population in UAE, for better effectiveness of service provision, there needs to be collaboration between the public and private sector at all levels.
4. These are very early days for ABA as an intervention for ASD in UAE, thus it is pertinent to create a standards and licensing policy for the same. All the experiences shared by parents point to the urgent need of professional

standardization of ABA services through a policy framework and practitioner guidelines for the consumers in the country. Although the field is new to UAE, the need for it is not any different from other countries.

5. There is a large gap between the need and availability of service providers. Building local capacity of service providers is an option that may help reduce the expense and the dependence on professionals from other countries. This would mean creating more teacher education & hands on training opportunities within UAE for ease of reach and expense. More effort in the area of awareness & education regarding Autism and ABA needs to be done in order for families to be able to make better-informed choices and exercise their rights as consumers.
6. If Parents, professionals and Non-governmental organizations collaborate and voice their thoughts together towards provision of Best Practice in Autism and specifically in ABA services; the movement would have more impetus.

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