# Attitudes of Parents of Children with Special Educational Needs and Disabilities towards Diagnosis and Intervention in Dubai and its Implication on Education

آراء أولياء أمور الأطفال ذوي الاحتياجات التعليمية الخاصة والإعاقات تجاه التشخيص والعلاج في دبي وتأثيرها على التعليم

by

## YOMNA EL HARIRY

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**Dr Eman Gaad**
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# Abstract

The purpose of this study was to identify the attitudes of parents of children with Special Educational Needs and Disabilities (SEND) towards diagnosis and intervention in Dubai. It aimed to explore the relationship between these attitudes and its effect on the academic performance of children with SEND. A mixed-methods approach was utilized that centered on a questionnaire-based survey as well as interviews with class teachers, SENCOs, learning support staff, school counselor and head of SEN department of a Dubai-based private school.

Mostly positive attitudes towards services provided from the diagnostic centers were depicted, including therapies and various intervention tools. Two main themes stood out during data analysis; the first focused on the financial strains parents had to endure in order to receive a diagnosis for their child followed by therapies and interventions, and the second focused on anxiety with regards to their children's future after they graduate from school and fear of the unknown.

Interviews conducted mainly focused on the implication of parents' attitudes towards their children's future in education. Participants from the educational field shared their thoughts and experiences, and all of them stressed the importance of early diagnosis and intervention in order to ensure the best possible social, emotional, and intellectual development of the child. The main themes that stood out from these interviews also included the financial pressure that most parents suffered in order to diagnose their children and provide therapies and intervention as well as the reliability of diagnostic reports received from accredited and authorized diagnostic centers and clinics.


**Key words**: SEND, diagnosis, intervention, education, Dubai

# ملخص

تهدف هذه الدراسة للتعرف على آراء أولياء أمور الأطفال ذوي الاحتياجات التعليمية الخاصة والإعاقة نحو التشخيص والتدخل في دبي والتي تهدف إلى استكشاف العلاقة بين هذه المفاهيم وتأثيرها على الأداء الأكاديمي للأطفال الذين يعانون من ذوي الاحتياجات التعليمية الخاصة والإعاقة.

تم استخدام نهج مدمج الأساليب التي تركز على المسح الاستبياني وكذلك مقابلات مع معلمي الصف، وموظفي دعم التعلّم، ومستشار المدرسة ورئيس قسم الاحتياجات الخاصة في مدرسة خاصة مقرها دبي.

وقد تم تحديد مواقف إيجابية في الغالب من الخدمات المقدمة من المراكز التشخيصية، بما في ذلك العلاج وأدوات التدخل المختلفة. وظهر أمران رئيسيان أثناء تحليل البيانات ركز الأول على الضغوط المالية على الآباء من أجل الحصول على تشخيص لطفلهم تليها العلاجات والتدخلات، والثاني تناول القلق فيما يتعلق بمستقبل أبنائهم بعد تخرجهم من المدرسة والخوف من المجهول.

وركزت المقابلات التي أجريت بشكل رئيسي على انعكاس مواقف الوالدين تجاه مستقبل أطفالهم في التعليم. قدم المشاركون من المجال التربوي أفكارهم وخبراتهم، وشددوا جميعا على أهمية التشخيص المبكر والتدخل من أجل ضمان أفضل لنمو اجتماعي وعاطفي وفكري ممكن للطفل. وشملت المواضيع الرئيسية التي نتجت من هذه المقابلات أيضا الضغوط المالية التي يعاني منها معظم الآباء من أجل تشخيص أطفالهم وتوفير العلاج والتدخل وكذلك القدرة على اعتماد التقارير التشخيصية الواردة من مراكز التشخيص والعيادات المعتمدة والمرخصة.

**الكلمات الرئيسية:** الاحتياجات الخاصة، التشخيص، التدخل، التعليم، دبي

# Dedication

To Yousuf, Adam & Aya.

May you flourish in a community more diverse, tolerant, and beautiful.

# Acknowledgement

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| | |
|---|---|
| UAE | United Arab Emirates |
| SEND | Special Educational Needs and Disabilities |
| SEN | Special Educational Needs |
| MOE | Ministry of Education |
| MOSA | Ministry of Social Affairs |
| KHDA | Knowledge and Human Development Authority |
| DHA | Dubai Health Authority |
| SENCO | Special Educational Needs Coordinator |
| CDA | Community Development Authority |
| FS | Foundation Stage |
| LD | Learning Difficulty |
| MLD | Moderate Learning Difficulty |
| SLD | Severe Learning Difficulty |
| PMLD | Profound & Multiple Learning Difficulty |
| DS | Down Syndrome |
| ASD | Autism Spectrum Disorder |
| CP | Cerebral Palsy |
| EBD | Emotional Behavioural Difficulty |
| IEP | Individualized Educational Plan |
| ZAD | Zone of Actual Development |
| ZPD | Zone of Proximal Development |
| ABA | Applied Behaviour Analysis |
| PhD | Doctor of Philosophy |

# Chapter One

## Introduction

The United Arab Emirates (UAE) Vision 2021 National Agenda states that "(e)ducation is a fundamental element for the development of a nation and the best investment in its youth" (n.d). Therefore, it emphasizes the development of a first-rate education system that requires a complete transformation of the current system and teaching methods. Significant investments are currently underway in order to promote and reinforce enrollments in preschools since the UAE believes early childhood development is crucial in shaping children's personalities and their future (Vision 2021, National Agenda).

One of the major transformations in the UAE's education system was turning it into an inclusive one. Significant legislative changes have been made to provide appropriate educational environments to meet the unique individual needs of diverse learners (Sands, Kozleski, & French, 2000). The basic concept of inclusion argues against segregation and discrimination of learners in schools (Avramidis, Bayliss, & Burden, 2000 in Haq & Mundia, 2012).

Inclusive education practice has taken many forms in different countries following the first World Conference on Education for All in Jomtein in 1990 (UNESCO, 1990), the adoption of the Salamanca Statement in 1994 (UNESCO, 1994) and the opening of the World Education Forum in Dakar in 2000. Its main spirit of including pupils with special needs into regular schools is now widely practiced around the world (Tsang, 2013). Ed. Brodie and Savage (2015) sum up inclusion by recognizing that people are individuals with a whole range of characteristics that make them different, and assume that those personal differences should not prevent anyone from taking part fully in any social, cultural and economic parts of life.

The UAE consequently followed suit by issuing federal law No. 29/2006 and later amended by Law No. 14/2009 in order to secure the rights of people with special needs (Alborna & Gaad, 2012). These laws were issued in accordance with the United Nation's convention on the rights of persons with disabilities. Article 2 in section one aimed to guarantee the rights of a person with special needs to be provided with all services within a community. Article 12 in Chapter Two focused mainly on guaranteeing a person with

special needs an equal opportunity in education in mainstream schools (MoSA, n.d). The Special Education Department in the Ministry of Education developed general rules for the provision of special education programs and services in the public and private sectors in order to enlighten parents and guardians of their children's rights as well as clarify to schools and institutions what is expected of them (MOE, n.d).

Schools have been informed and notified of the federal laws issued in support of disabled children and have henceforth taken the initiative towards inclusion. The Ministry of Education (MOE) as well as the Knowledge and Human Development Authority (KHDA) have been inspecting private and public schools since 2007 in order to ensure world standard quality of education as well as guarantee the inclusion of disabled children in mainstream schools (KHDA, 2014). Schools, thereby, established Special Educational Needs (SEN) departments and developed training programs for teachers and assistants in order to equip them with efficient teaching policies and practices. Likewise, school environments were restructured for accessibility.

## 1.1 Identification, Assessment and Intervention in Dubai

Identification, assessment and intervention of Special Educational needs and Disabilities (SEND) is a much-debated topic in the UAE. Education is granted and is compulsory up to grade 9 for UAE nationals who comprise of 20% of the population (Gaad, 2011). The remaining 80%, who are expatriates, are expected to pay for their children's education. The education provided in the UAE mainly depends on what the parents can and cannot afford. There are numerous private schools with fees ranging from affordable to extremely expensive, and the quality of education is consequently reliant on the parents' financial state.

According to Kauffman & Landrum (2013), there are four stages of assessment including screening, eligibility, evaluation for instruction and classification. Screening refers to a brief procedure that samples a few traits with the purpose of identifying students whose behaviour or performance may be indicative of a serious problem or who should be assessed more thoroughly. Eligibility suggests formally referring students whose targeted interventions have not resulted in functioning improvement for special education evaluation. These students are then exposed to additional assessments specifically administered for the purpose of planning instructional methods.

Screening and eligibility are consequently being performed at schools, but further assessments are necessarily conducted by qualified psycho-educationalists practicing in certified medical centers throughout the UAE (DHA, 2016). Schools do not place students on special education programs or accept new admissions for children with special needs unless formal medical reports are submitted. Assessment that is directly linked to intervention is most useful for educators who plan and implement instructions since assessment, identification and classification of students with SEND is critical prior to the development of Individualized Education Plans (IEP) (Kauffman & Landrum, 2013).

Back in 1972, Gallagher proposed a special educational contract in order to protect children with disabilities against incorrect and unnecessarily placements as well as to hold educators accountable for their students' progress (Wamba & Dunn, 2009). This proposition was integrated in a 1975 law named 'Education for all Handicapped Students Act' or Public Law 94-142 in the form of an Individualized education plan or IEP. Nowadays, designing an IEP for students with SEND included in a mainstream school is considered a necessity and a basic requirement and right.

Inclusion is such a detrimental concept since it signifies an intense shift away from educational policies and practices that are based on selection (ed. Richards & Armstrong, 2011). It stresses on the right of every member of society to participate and have access to education equally. This deems challenging for most students attending private schools in the UAE, and particularly so for those with SEND.

Having children labeled with SEND in the UAE places heavy financial burden on families since schools request for shadow teachers who they either charge additional fees for or expect to be outsourced by parents. Furthermore, children are expected to religiously attend weekly therapies, which are mainly offered through private clinics. Governmental entities such as the Community Development Authority (CDA) provide services for the UAE nationals since they plan and implement a set of programs and services for the welfare of society (2015). Even though the UAE nationals are the minority, the CDA has an extended waiting list due to limited centers and resources compelling most parents to enroll their children in private centers and clinics. Thereby, many parents shy away from assessing their children, in order to avoid the social stigma

as well as the financial and medical hassle associated with a child labeled with SEND in the UAE.

## 1.2 Rationale

In mainstream schools, teachers voice their concerns to the Special Educational Needs Coordinators (SENCOs) in order to observe certain children's academic, behavioral and social developmental levels. With sufficient observational notes and documentation, SENCOs may approach parents to express their concerns and recommend having the children assessed at an intervention center or a certified clinic that can medically diagnose. Only then can a school provide necessary strategies and support for the child at the school. In cases where parents appear uncooperative, the school may reach out to governmental entities such as the KHDA in Dubai to legally decline admission of the child for the following academic year.

Parents, thereby, find their children facing either SEND diagnoses or academic exclusion. Naturally, this route led to a market boost in child medical and intervention centers in the Dubai offering various services and facilities. Inclusion is looked upon as an approach to develop education as well as society as a whole, but even though many schools strive to value all children equally despite the labeling, these categorizations negatively affect the wider perceptions of society (Booth & Ainscow, 2011).

There has been extensive research with regards to diagnosing children with SEND and how intervention correlates to academic and social achievement. Unfortunately, the UAE lacks research of the like, and opinions of parents who are being compelled to retrieve diagnoses and intervention for their children remain unknown and unexplored. By exploring parents' attitudes towards diagnoses and intervention in Dubai, light can be shed on the future of inclusive education while highlighting challenging areas of development. The study also aims to explore the relationship between these attitudes and the children's performance in academics.

As the aim of the research was to measure and identify attitudes, a mixed methods approach of quantitative and qualitative processes, known as triangulation, was chosen as the research methodology. This study included questionnaires, individual and group

interviews. "(T)he key to triangulation is to see the same thing from different perspectives and thus be able to confirm or challenge findings of one method with those of another" (Bell, 2010, p.118).

"A survey design provides a quantitative or numeric description of trends, attitudes, or opinions of a population by studying a sample of the population" (Creswell, 2009, p.145). This quantitative approach is much needed in order to collect data in a systematic and organized style, data that could be measured, analyzed and presented in a relevant manner. Semi-structured individual and group interviews were also administered in order to gain views of parental attitudes from the perspective of class teachers, managers, coordinators and SEN staff.

## 1.3 Research Questions

In order to identify parental attitudes towards diagnosis and intervention of SEND children in Dubai and its implication on their education, this study asks the following questions:

1- How do parents feel about having their young children assessed for SEND?
2- How satisfied are parents with the services provided in Dubai with regards to child intervention centers and clinics?
3- Do parents genuinely believe that intervention and therapy affects their children's performance at school?
4- To what extent is diagnosing a child with SEND and exposing them to intervention at an early age significant to their future in academic achievement?

## 1.4 Limitations

A major limitation of this study was the lack of statistical data offered by the UAE government. Statistics with regards to children with SEND would have created a reliable platform from which further studies could have been initiated.

Having parents respond to the questionnaire was also a limitation since it was narrowed down to those who had children with SEND. A lot of sending and resending and

following up was required in order to receive a total of 25 responses. Unfortunately, a number of these responses were incomplete as well. The small number of participants has its implication on the representativeness of the research findings, as the findings are solely limited to their perceptions.

Despite the limitations faced in conducting this study, it is hoped that the findings would shed light into the attitudes and beliefs of parents of children with SEND with regards to diagnosis and intervention in Dubai and its implication on education.

# Chapter Two

## Literature Review

This section of the study explores the literature in the areas of SEND, identification and assessment, early intervention, and parental role. It aims to highlight the significance of parental attitudes towards children's future in academia.

## 2.1 Children with Special Educational Needs and Disabilities

Academic attainment is the starting point for looking at special educational needs. There are grounds for concern when children are not progressing and learning roughly at the same pace as their peers. Learning difficulties may be temporary or permanent, short-term or long-term. According to Alcott (2002), a list of SEN can be adopted using the 'Code of Practice', and include the following:

- Learning Difficulties (LD)
    - Moderate (MLD)
    - Severe (SLD)
    - Profound and Multiple (PMLD)
- Specific Learning Difficulties
    - Such as dyslexia, dyscalculia, and dyspraxia
- Emotional and Behavioural Difficulties (EBD)
- Physical Disabilities
- Sensory Impairment
    - Hearing Difficulties
    - Visual Difficulties
- Speech and Language Difficulties
- Medical Conditions
- Intellectually Gifted and Talented

## 2.1.1 Learning Difficulties

Alcott stresses that "(a)ll children with learning difficulties show academic attainment that is significantly below that of their peers in most subjects of the curriculum. They usually have serious problems with basic skills of reading, writing and working with numbers" (2002, p.31).

Children with Moderate Learning Difficulties (MLD) exhibit attainment well below expected levels in all or most areas of the curriculum, despite appropriate interventions. Their needs cannot be met by regular differentiation and flexibilities of the curriculum. Students with MLD have greater difficulties than their peers to acquire basic literacy and numeracy skills and in understanding concepts. They may also have associated speech and language delay, low self-esteem, low levels of concentration and underdeveloped social skills (Frederickson & Cline, 2009).

Children with Severe Learning Difficulties (SLD), on the other hand, have significant intellectual or cognitive impairments, which, consequently, affect their ability to participate in the schools curriculum without support (Frederickson & Cline, 2009). "They may also have associated difficulties in mobility and coordination, communication and perception and acquisition of self-help skills" (p.308).

Students with Profound and Multiple Learning Difficulties (PMLD) have severe and complex learning needs; they also have significant difficulties, such as physical disabilities, or sensory impairment (Frederickson & Cline, 2009). They require a high level of adult support, both for their learning needs and personal care.

## 2.1.2 Specific Learning Difficulties

Specific learning difficulties is an umbrella term which indicates that pupils display differences across their learning. Frederickson & Cline identify children with special learning difficulties as having particular difficulties in learning to read, write, spell or manipulate numbers and so their performance in these areas are significantly below their peers. They may also have problems with short-term memory, organizational skills, and coordination. Children with special learning difficulties cover the whole ability range and the severity of the impairment varies widely. Specific learning difficulties include

dyslexia, dyscalculia, and dyspraxia (2009, p.308). Often, an outcome of specific learning difficulties is a high level of frustration that can consequently lead to Emotional and Behavioural Difficulties (Alcott, 2002).

## 2.1.3 Emotional and Behavioural Difficulties

Children who present Emotional and Behavioural Difficulties (EBD) often struggle to achieve their potential in academic terms. Emotional problems regularly affect their academic achievement and emerge through their behaviour. They engage in "difficult behaviour that is more persistent over time and pervasive across different settings" (Frederickson & Cline, 2009, p.409). The range of EBD is considerable, but Alcott simplifies it to a few possible symptoms, including:

- Obsessions
- Withdrawal from social interactions
- Apathy
- Tempter tantrums
- Bullying
- Eating disorders
- Phobias
- Stealing
- Lying
- Vandalism
- Truancy (2002, p.42)

## 2.1.4 Physical Disabilities

Physical impairments may lead to physical disabilities. The impairment may have a congenital origin, or may be a result of accident or illness. Physical disabilities could be of short or long duration, and could be mild or severe. Some children often have a combination of impairments; a child with CP may have sensory impairment, learning

difficulties, speech and language difficulties, as well as motor impairment. According to Alcott (2002), these children require highly complex needs.

On another note, many children with physical disabilities prove high achievers in their academic work. Their special needs are principally focused on accessibility. Depending on the nature of their disability, children will require support and assistance in certain subjects of the curriculum, such as Physical Education, or adaptations to certain equipment, such as technology or computer work.

## 2.1.5 Sensory Impairment

There is a wide range of hearing impairment in children, ranging from mild to severe hearing loss. Alcott mentions that many children with mild and moderate hearing impairment can cope in mainstream schools with appropriate resources, while a small minority requires specialist provision that can only be provided in special schools (2002, p.48). Secretory otitis media, or 'Glue ear' as is it is most commonly known, is fairly common in the primary years and is easily treatable, but permanent hearing loss usually leads to significant communication difficulties. Unfortunately, there is also the risk of children with hearing impairment consequently developing EBD due to frustration in communication attempts.

Similar to hearing impairment, visual impairment vary considerably in severity and degree. It occurs due to a malformation or malfunction of the eye, optic nerve, or the visual system within the cerebral cortex (Frederickson & Cline, 2009). Problems in the visual system include genetic factors, infectious diseases during pregnancy, and diseases and injury during birth or childhood (p.518). Alcott (2002) explains that the range spans minor visual impairment, partial sightedness and blindness. It is estimated that 50% of children with visual impairment may also have SLD or PMLD.

## 2.1.6 Speech and Language Difficulties

Language is central to human experience, and a key vehicle for thought and social interaction. According to Frederickson & Cline (2009), effective communication requires

skill in phonology and syntax, semantics as well as pragmatic, conversational, and sociolinguistic competence. Children having problems mastering some or all of these communication areas are usually diagnosed with speech and language difficulties. Speech and language difficulties can also lead to serious challenges for children to progress at schools. It often leads to frustration, which easily develops into behavioural problems. Olswang et al. (2001 in Frederickson & Cline, 2009) remark that in the past, most attention was given to the first two types of competence; knowledge of language forms (phonology and syntax) and knowledge of its meaning (semantics). "But it is increasingly being recognized that children who have problems in other aspects of language competence, such as pragmatic competence, are just as impeded in communicating effectively with other people as they would be if the sounds of their speech were distorted or their vocabulary limited" (p.241).

Speech and language difficulties can be considered from a medical or linguistic angle (Alcott, 2002). The medical approach focuses on the causes of speech and language problems, such as hearing loss, brain damage, or cleft palate. The linguistic approach, on the other hand, focuses on the nature of the child's difficulties in speech and language rather than on the causes. A battery of tests is often conducted for children with speech and language difficulties in order to analyze their use of expressive and receptive language. Alcott continues to explain that a number of children have what is known as secondary language impairments. "(A)ny child with serious hearing loss or learning difficulties that are either severe or profound and multiple may also have speech and language difficulties" (2002, p.53).

## 2.1.7 Medical Conditions

Various medical conditions, depending on their severity, may eventually lead to learning difficulties. Common conditions such as heart disease, cancer, epilepsy, cystic fibrosis, diabetes, and asthma, can cause learning difficulties due to:

- Prolonged periods spent in hospitals
- Regular visits to hospitals over a number of years
- Medication that impact learning ability
- Deterioration of physical condition over time

- Emotional problems related to medical condition (Alcott, 2002)

It is worthy to note that hundreds of conditions may lead to learning difficulties for children. It is helpful to think of these conditions as being in two broad groups – internal and external (Alcott, 2002):

- Internal conditions are related to the body and mind of children, such as impairment of limbs, disease, deficiencies or damage to organs of the body, emotional and psychological disorders.
- External conditions refer to the quality of the environment in which children are brought up in, such as family, school and the community they live in.

The CAF Directory of Specific Conditions and Rare Syndromes (Alcott, 2002, p.57-67) has a comprehensive listing of conditions that may lead to learning difficulties. Some of the most common conditions, listed in alphabetical order, include:

- Asperger syndrome – a variation of Autism Spectrum Disorder
- Asthma – difficulty in breathing due to blockage of airways
- Attention Deficit Hyperactivity Disorder (ADHD) – includes symptoms such as difficulty paying attention, impulsive behaviour, hyperactivity, excessive talking, and unawareness of danger
- Autism Spectrum Disorder (ASD) – children with ASD typically display social interaction problems, communication problems, rituals and inflexibility
- Cancers and Leukaemia
- Cerebral Palsy – caused by damage to the brain during pregnancy or delivery and affects the part that controls movement. As a result, children with CP may develop motor problems, visual and hearing impairment, speech and perceptual difficulties
- Cystic Fibrosis – a disorder that affects the lungs and pancreas
- Deaf/Blind Rubella
- Diabetes
- Down Syndrome – a genetic disorder in which a person has an extra chromosome 21 that can lead to hearing and visual problems, delayed development, and a 40% chance of heart problems at birth
- Dyslexia – difficulties in reading, spelling and writing

- Dyspraxia – difficulties with physical movement, delayed language development, and perceptual problems
- Epilepsy – caused by a temporary disturbance in brain function leading to seizures
- Hearing impairment
- Heart defects
- Speech and language impairment
- Spina bifida – develops in the growing foetus where the spinal cord develops a malformation in which the vertebrae fail to form properly and affects the child physically and intellectually
- Visual Impairment

## 2.1.8 Intellectually Gifted and Talented

Gifted children present advanced cognitive and developmental abilities. This label covers a broad range from mildly gifted, to extremely gifted, referring to advancement in all developmental areas, to gifted or talented in one or more areas. Talented children have one or more special abilities such as in music, art, or mathematics. Paasche, Gorill, & Strom (2004) mention that Gifted young children can be identified by their advanced abilities when compared with children of their same age. Some of the basic characteristics of Gifted children include grasping and understanding new ideas quickly, being curious, having a retentive memory, presenting leadership skills, having superior conversational skills and advanced reasoning ability (p.84).

## 2.2 Identification and Assessment

The assessment of young children with delays or disabilities is an integral component of early intervention and early childhood special education. According to Gargiulo & Kilgo (2014), assessment is a broad term and can be viewed in many definitions collectively. Years ago, Bagnato and Neisworth (1991) emphasized that early childhood assessment was a flexible, collaborative, decision-making process in which teams comprised of families and professionals repeatedly revised their judgments and made decisions. Richard and Schiefelbusch (1991) even described assessment as a multi-level process,

beginning with screening procedures and continuing through diagnosis, planning of intervention, and program monitoring and evaluation. McLean, Wolery, and Bailey (2004) provide a simple definition that explains that assessment is the process of gathering information for decision-making. These definitions suggest that assessment is a dynamic, ongoing process allowing for various decisions to be made about children with special educational needs and disabilities (Gargiulo & Kilgo, 2014).

Children with severe problems are usually identified before school entry, but according to Frederickson & Cline (2009), less obvious difficulties are difficult to identify with certainty. In reality, many different types of assessment take place simultaneously and on several different levels. Rather than referring to a 'test', assessments are a systematic process for obtaining information from a variety of sources including observations, interviews, portfolios, and assessment instruments in order to make judgments about a child's characteristics, needs, and progress (Gargiulo & Kilgo, 2014). Assessment information gathered are used in decision-making in one or more of the following areas:

1- Screening – a procedure designed to identify children who need to be referred to further in-depth assessment.
2- Eligibility – a comprehensive diagnostic process to determine if a child meets the criteria to be eligible for services.
3- Program planning – a procedure used to identify desired outcomes/goals for Individualized Educational Plans (IEP) and how to design instruction.
4- Progress monitoring and evaluation – a process of collecting information about a child's progress towards outcomes, the family's satisfaction with services, and the program's effectiveness (p.98).

"These different assessment purposes necessitate various instruments and procedures to be used by qualified professionals representing multiple disciplines" (p.87), including childhood special educators, physical therapists, speech-language pathologists, and nurses.

Since early childhood is a unique period of development, different types of assessment instruments and procedures have been developed specifically for young children. According to Gargiulo & Kilgo (2014), common assessment procedures in early childhood special education include norm-referenced tests, criterion- or curriculum-based

instruments, observations, and interviews amongst other measures. Alongside standardized measures, informal assessment measures that are less prescriptive and more specific to the context are recommended (p.88).

## 2.2.1 Formal Testing

Formal testing has been the procedure most frequently used during the initial phases of assessment. However, Gargiulo & Kilgo (2014) stress the limitations that have been described by some professionals as "a predetermined collection of questions or tasks to which predetermined types of responses are sought" (p.88). Basically, norm-referenced tests provide information about how a child is developing in relation to a larger group of children of the same age. They are popular for their eligibility purposes, report reliability and validity information, and are usually administered in short periods of time. Dockrell (2001 in Frederickson & Cline, 2009) argues that norm-referenced assessment tools and questionnaires for parents or professionals are not sufficiently reliable with young children with screening purposes, since some language and communication difficulties only become apparent when a child is faced with challenges posed by school.

## 2.2.2 Criterion and Curriculum-based Assessments

Criterion-referenced assessments are used to determine whether a child's performance meets established criteria within various developmental domains, such as cognitive, motor or self-care (Gargiulo & Kilgo, 2014). Curriculum-based assessments are similar but with the main focus being on a child's performance in relation to specific curriculum content. These types of assessment instruments are more relevant for program planning purposes according to Cohen & Spenciner and Sattler (2007; 2008 in Gargiulo & Kilgo, 2014).

### 2.2.3 Authentic Assessment

"A type of assessment approach that is based on the premise that the behaviour of young children must be observed in natural settings during real-life situations is authentic assessment" (Gargiulo & Kilgo, 2014, p.90). This comprehensive term is used to represent the process of observing, recording, collecting, and documenting what children do and how they do it for the purpose of making educational or intervention decisions (Keilty, LaRacco, & Casell, 2009; Losardo & Notari-Syverson, 2011 in Gargiulo & Kilgo, 2014). Observational assessment is an example of the way in which authentic information can be gathered. Play-based assessment is a fairly common observational procedure used in early childhood education for infants, toddlers and preschoolers. Interviews or conversations between professionals and caregivers are another form of assessment used to gather information about the areas on which to focus during assessment processes.

### 2.2.4 Dynamic Approaches to Assessment

Frederickson & Cline (2009) also discuss dynamic approaches to assessment that are based on a social constructivist view of child and adolescent development. "In this view, deriving from Vygotsky's ideas, higher-order mental processes develop on the basis of cooperating with other people, on later becoming 'inner, individual functions of the child itself'" (p.329). Thereby, parents or caregivers, peers and teachers are seen as playing a crucial mediating role in stimulating children's learning from infancy.

> In this view learning is constructed jointly through special interaction, and understanding can be enhanced by the appropriate amount of assistance, finely tuned to what children know and can do. The emphasis is on potential rather than maturation and readiness, and the role of the 'more knowledgeable other' person is immensely important.
>
> (Watson 2000: 135 in Frederickson & Cline, 2009)

Static tests, thus, evaluate what a child has learned in the past or in their Zone of Actual Development (ZAD). Many believe it is of more importance to assess, what Vygotsky calls, their Zone of Proximal Development (ZPD), which can only be derived through

dynamic measures (Frederickson & Cline, 2009). The ZPD refers to the level of development immediately above the person's present level (Slavin, 2014).

## 2.2.5 Behavioural, Cognitive, Psychodynamic, and Systemic Approaches

Certain difficulties require a battery of assessments derived from diverse theoretical perspectives in order to make a reliable conclusion. Frederickson & Cline (2009) state four theoretical perspectives typically used to gather information about a child.

| | |
|---|---|
| Behavioural | Information gathered regarding the frequency and duration of target problematic behaviours and the environmental events surrounding the occurrence. |
| Cognitive | Information about the parents or caregivers' perceptions, interpretations and feelings about the child's behaviour and the actions taken by the school. |
| Psychodynamic | Information about the child's early development and family relationships, paying particular attention to experiences seen as having had crucial emotional significance. |
| Systemic | Information about the parents or caregivers' perceptions and their interpretation of the perceptions of others, such as the child and their teachers. Their hypotheses about ways in which everyone involved would be affected by particular changes. |

Ultimately, complete assessments include information about how to facilitate children's development and the supports that are needed to help them exhibit desirable behaviour (ed. Shonkoff & Meisels, 2000). Assessment and intervention should, thereby, be an interactive process in which each informs the other since children's development is "a moving target of skills, knowledge, experiences, dispositions, and personality variables" (p.236).

## 2.3 Early Intervention

In earlier times, early intervention was described as the process of intruding upon the lives of young children with disabilities and their families for the purpose of altering the direction and consequences of a disability or delayed development (Fallen & Umansky, 1985). Experts state that "the action required is individual, but it encompasses any modification or addition of services, strategies, techniques, or materials required to maximize the child's potential" (p.160).

Recently, in synthesizing the thinking of former educators and researchers, Hallahan, Kauffman, and Pullen (2009 in Garguilo & Kilgo, 2014) echo earlier perspectives and offer the following rationale for early intervention:

- A child's early learning provides the foundation for later learning, so the sooner a special education program or intervention is begun, the further the child is likely to go in learning more complex skills.
- Early intervention is likely to provide support for the child and family that will help prevent the child from developing additional difficulties.
- Early intervention can help families adjust to having a child with disabilities; by giving parents or caregivers the skills they need to handle the child effectively at home and by helping families find the right support services they may need such as counseling, medical assistance, or financial aid.

Therefore, collectively, "the aim of early intervention is to affect positively the overall development of the child's social, emotional, physical, and intellectual well-being" (Garguilo & Kilgo, 2014, p.41). This whole-child approach is important because these aspects are interrelated and dependent on each other (Zigler, 1990).

Over the years, educators and social scientists have identified a variety of reasons why early intervention is important for young children with disabilities and children at risk. Many of these reasons are derived from research evidence, theoretical arguments, expert opinion, and societal values (Guralnick & Conlon, 2007; Hanson & Lynch, 1995; Howard, Williams, & Lepper, 2010; Raver, 2009; Shonkoff & Meisels, 2000).

Some of these explanations include a belief that early environmental stimulation can positively facilitate subsequent development and readiness for learning. A sensitive or

critical periods hypothesis suggests that intervening during key periods in a child's life is vitally important if the child is to acquire more complex skills and competencies later on (Allen & Cowdery, 2012). The intensity of these early intervention efforts can also substantially influence outcome effectiveness (Guralnick & Conlon, 2007; McCormick et al., 2006). Also, an assumption that early intervention can minimize the impact of a particular disabling condition and can possibly prevent or attenuate the occurrence of secondary disabilities (Bailey et al., 2005). The proposition is that intervention programs can ameliorate learning deficits and problems frequently attributed to certain risk factors such as environmental conditions (Lipkin & Schertz, 2008). Benefits that accrue to families of young children with special needs and children at risk can candidly be related to early intervention. Early childhood special education professionals can assist families by providing factual information, emotional support, and specific training (Bailey et al., 2005). These benefits eventually extend beyond the child and the family to society at large.

Early intervention for children with disabilities has definite advantages for society, the family, and, of course, the child. Early childhood special education can make a significant difference in the quality of life for young children with special needs and their families. In fact, early intervention as a strategy to prevent later problems has almost become conventional wisdom (Kamerman, 2000 in Garguilo & Kilgo, 2014). Scientists have been able to consistently demonstrate that well-designed early intervention programs produce positive outcomes according to their intended purpose (Bailey, 2000; Guralnick & Conlon, 2007; Ramey & Ramey, 1998; Zigler, 2000). Conclusions reached by Shonkoff and Phillips found that high-quality, well-designed early intervention programs "have been shown to influence the development trajectories of children whose life course is threatened by socioeconomic disadvantage, family disruption, and diagnosed disability" (2000, p.11).

## 2.4 Parental Involvement

Parental involvement in children's education is believed to be a major component of many school reforms (Comer, 1996) and of early childhood programs (Zigler & Muenchow, 1992). Miedel & Reynolds (2000) state that parental involvement in early

elementary school may be an important way to start children on the right path toward school success since it may be influential on children's adaptation to the school environment.

Research with regards to the benefits of parental involvement in children's early education years has stirred controversial results between professionals. According to Miedel & Reynolds (2000), some researchers reported a positive relation between parent involvement in early schooling and child achievement (e.g., Henderson & Berla, 1994; Marcon, 1998; Reynolds et al., 1996; and Slaughter et al.; 1989), while others found no evidence to support this claim ( e.g., Barnett et al., 1998; White, 1985; and White et al., 1992).

In a review of early intervention literature, White and colleagues (1992 in Miedel & Reynolds, 2000) concluded that the involvement of parents in early intervention programs does not produce benefits for children. On the other hand, several early intervention program studies that examined academic achievement found that parent involvement was positively associated with children's school success (Lally et al., 1988; Olmsted, 1991; Reynolds, 1989; Reynolds, 1992 in Miedel & Reynolds, 2000). Marcon (1998) found similar results concluding that the more involved parents were in kindergarten, the fewer special education placement and less grade retention there were for children in sixth and seventh grade. Perhaps parents who monitor their child's school performance and are available to communicate with the teachers are more likely than other parents to know of their child is having difficulty in school (Miedel & Reynolds, 2000). Thus, parents intercede before special education placement or grade retention becomes necessary.

There are different hypotheses that attempt to explain how early intervention participation leads to long-term school success in children. Some explain this process as attributable to "the child's increased cognition due to early intervention that continues through school" (Miedel & Reynolds, 2000, p.4). Other hypotheses explain children's school success is based on school motivation or adjustment that is enhanced through the early intervention experience (Reynolds, 1999).

In one of the first reviews of early intervention research, Bronfenbrenner concluded that "without family involvement, intervention is likely to be unsuccessful, and what few

effects are achieved are likely to disappear once the intervention is discontinued" (1974, p.300). However, there still remains inconclusive evidence that a parent involvement component is an essential part of early intervention programs for children with special needs or disabilities (Miedel & Reynolds, 2000).

# Chapter Three

## METHODOLGY

This study aimed to identify and understand attitudes of parents of children with special educational needs and disabilities towards diagnostic and intervention services offered in Dubai. Although there is still no universally accepted definition for attitudes, most researchers agree on certain aspects, most prominently the assumption that attitudes are constructs with affective, cognitive, and behavioural components (Olson & Zanna, 1993 in Findler, Vilchinsky & Werner, 2007). "Attitude is an idea charged with emotion which predisposes a class of actions to a particular class of social situations" (Triandis, 1971, p.2). More recent definitions refer to the cognitive component as an individual's ideas, thoughts, perceptions, beliefs, opinions, or mental conceptualization of the referent (Findler, Vilchinsky & Werner, 2007). Furthermore, this study aimed to explore the relationship between these attitudes and its implication on the children's academic performance.

In this section, the research methodology and research tools are explained highlighting the use of the mixed methods approach.

## 3.1 Research Method

Research contributes to existing information about issues and suggests improvements for practice. It further helps practitioners evaluate approaches that will work for individuals in educational settings (Creswell, 2008). "Research on special needs education is often very complex and puts specific demands on the methodology used. Data-triangulation, at the very least, is required" (Ghesquie`re, Maes & Vandenberghe, 2004, p.17).

Traditionally, triangulation is the process where sailors use multiple reference points to locate an object's exact position at sea (Jick, 1979 in Creswell, 2008). Conventionally, the term is used in research and means investigators could improve their inquiries by collecting and converging different kinds of data bearing on the same phenomenon. Creswell (2008) emphasizes that triangulating or converging data in a single study continues to be an attractive approach to mixed methods research today.

There is a growing consensus among researchers that qualitative and quantitative research can complement each other. A review of quantitative studies about a particular phenomenon combined with a review of qualitative studies about the same can provide richer insights and raise extremely interesting questions for future research (Gall, Gall & Borg, 2007). This approach has come to be known as mixed methods research. As defined by R.Burke Johnson and Anthony Onwuegbuzie mixed methods research is "the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study" (in Gall, Gall & Borg, 2007, p.33). The core argument for a mixed methods design is that the combination of both forms of data provides a better understanding than either quantitative or qualitative data by itself can offer (Creswell, 2008). It is considered to be a "legitimate inquiry approach" since it consists of merging, integrating, linking, or embedding the two strands (Brewer & Hunter, 1989, p.28).

Quantitative data produce results to assess the frequency and magnitude of trends, and can provide useful information regarding large number of people. Qualitative data, however, offer many different perspectives on the study topic and provide a complex picture of the situation (Creswell, 2008). Thereby, by assessing both outcomes of a study as well as the process, "a complex" picture of social phenomenon can be formed (Greene & Caracelli, 1997, p.7).

Therefore, for this specific study, a mixed methods approach employing a combination of questionnaires, individual and group interviews, has been applied.


## 3.2 Questionnaire Distribution and Site Selection

The questionnaire was distributed online through various media including emailing parent databases and social media. Three schools, two nurseries, one intervention clinic, the Community and Development Authority (CDA), and the UAE Down Syndrome Association were approached in order to email the questionnaire to their parents' database. The questionnaire was also circulated through parents' 'whatsapp' groups in various schools as well as public 'Facebook' pages.

The interviews were conducted in a school and nursery where the researcher formerly worked. Shenton & Hayter (2004) guarantee that previous connections with an organization chosen for a study can be of extreme added value. The chosen school is a private school following a British international curriculum and has been in operation for over 30 years in Dubai. The nursery is a division of the school and education is offered to year 13. The school and nursery have been practicing inclusive policies since 2012.

## 3.3 Organizational access

The researcher contacted the school principal via e-mail requesting permission to conduct the research at the school (Appendix 1). The purpose of the research, methodology, and all ethical considerations were explained verbally to the principal, thus replying to the email approving the research to be conducted. After obtaining permission, the researcher met with the school counselor and head of SEN in order to further explain the research and identify possible participants.

## 3.4 Sample Selection

Gall, Gall & Borg define the target population as "members of real or hypothetical set of people, events, or objects to which researchers wish to generalize the results of their research" (2007, p.166). Therefore, with regards to the survey, the target population was parents of children with SEND.

Purposeful sampling, on the other hand, was utilized for the qualitative segment of the study. Michael Patton describes the goal of purposeful sampling is to select cases that are likely to be "information-rich" with respect to the purposes of the study (in Gall, Gall & Borg, 2007, p.178). Replications were also carried out in order to increase the confidence in and extend the findings obtained. The following criteria were taken into consideration when selecting participants for the individual and group interviews:

- Participants had experience dealing with SEN children and dealt directly with parents or caregivers.
- Participants were willing to participate in the research.

- Participants were able and willing to share their views.

The tables below represent participants' profiles for individual and group interviews and discussions. Pseudonyms have been employed in order to protect their anonymity.

| Participant | Professional Status |
|---|---|
| Mona | Nursery Manager with over 15 years of experience in management in Dubai |
| Amy | Nursery teacher and team leader with over 16 years of experience with young children 3 – 5 year olds in Dubai |
| Noor | Nursery teacher with over 10 years of experience working with young children 2 – 4 year olds in Dubai |
| Priya | FS2 teacher with over 12 years of experience working with children 4 – 6 year olds in Dubai |
| Rosalinda | FS2 teacher with over 4 years of experience working with children 4 – 6 year olds in Dubai |
| Ameera | FS Learning support working in the SEN department for over 5 years with previous experience as a Year 1 teacher working with children 5 – 6 year olds for 3 years |
| Katie | Licensed nurse and therapist at an early intervention center in Dubai with over 8 years of experience |
| Table 1.1: Interview participant profiles | |

| Participant | Professional Status |
| --- | --- |
| **Group 1** | |
| Jane | School Counselor and Head of SEN with over 20 years of experience in the field in Dubai |
| Deepti | Former Nursery and Foundation Stage SENCO with over 7 years of experience in Dubai |
| **Group 2** | |
| Sally | Nursery and Foundation Stage SENCO with over 3 years of experience in Dubai |
| Golnar | FS Learning support working in the SEN department for over 5 years with previous experience as a FS2 teacher working with children 4 – 6 year olds for over 8 years |

Table 1.2: Group interview participant profiles

## 3.5 Research Tools

In this study, the collection and analyses relied mainly on nonexperimental descriptive methods based on participants' responses. The purpose of this descriptive research is to describe features and provide a broad picture of a condition or phenomenon by getting opinions and information from people (Boudah, 2011). This information can be the basis for comparisons or experimentation in future studies while providing quantitative, statistical results. No manipulation of variables of experimentation took place in this research.

Data collection methods included a questionnaire distributed to parents of children with SEND, semi-structured individual and group interviews and discussions with school educators and coordinators. According to Boudah, survey methods include the use of interviews or completion of questionnaires to yield data from respondents. They are generally used to measure attitudes, decisions, needs, behaviour, lifestyles, affiliations, and/or demographics of the sample chosen (2011).

## 3.5.1 Questionnaire

Individual items in a questionnaire each elicit a different bit of information and are considered a one-item test. However, when questions assess attitudes, the one-item test approach is questionable with respect to both validity and reliability (Gall, Gall & Borg, 2007). Therefore, a "questionnaire that measures attitudes generally must be constructed as an attitude scale and must use a substantial number of items in order to obtain a reliable assessment of an individual attitude" (p.235).

When preparing survey questionnaires, the potential inclusion of existing questions is a possibility that is not often contemplated by many researchers, despite it being feasible. Hyman, Lamb and Bulmer (2006) note one of the main advantages of using pre-existing questions from major social surveys is that they have been extensively tested at the time of use. Hence, for the purpose of measuring attitudes of parents of children with SEND towards diagnosis and intervention in Dubai, a pre-existing questionnaire designed by Warren Mansell and Kathleen Morris for their survey on "Parents' reactions to the diagnosis of an autistic spectrum disorder by a local service" has been employed and adapted accordingly.

Parents were emailed an eight-page (fourteen questions) questionnaire designed to assess the positive and negative consequences of a diagnosis and their attitudes towards it. The email outlined the nature of the study and explained that replies were anonymous and confidential (Appendix 2). The questionnaire was a mixture of a five-point Likert scale and spaces for additional comments. Likert scale allows participants to respond to statements with varying degrees of agreement or disagreement (Boudah, 2011).

The questionnaire first asked parents to provide information on the sex of the child, age, diagnosis and age of diagnosis and to identify the person responding to the questions as well as their educational background. Next, the parents were required to rate their satisfaction with the diagnostic service in several domains thus including a quantitative measure to the positive and negative consequences of the diagnosis. A range of statements generated from first-hand clinical experience and from a review of published papers then followed and parents were asked to rate how much they agreed with each one with respect to their child (Mansell & Morris, 2004).

Since Mansell & Morris' questionnaire targeted parents of children diagnosed with only Autism Spectrum Disorder (ASD), the part of the questionnaire regarding the types of ASD seemed unrelated and, thus, was not included in the survey. Furthermore, 'recommendations for the local diagnostic service and parents' support group' section deemed also irrelevant and quite lengthy, and therefore was also not incorporated. Minor modifications, eliminations and additions were conducted to the remaining sections in order to adapt the questionnaire to the target population in Dubai (refer to Appendix 3.1 – 3.6).

**Section 'A'** of the questionnaire focused mainly on demographics and included:

- Sex of the child
- Age of Diagnosis
- Diagnosis
- Who is completing the Survey
- Educational background of person completing the survey

**Section 'B'** determined the ratings of the diagnostic procedure by a series of statements which participants had to rate on a Likert scale ranging from "1-not at all", "2-somewhat", "3-neutral/unable to judge", "4-moderately", "5-extremely". These statements included:

- How sensitive were the local diagnostic service team in giving the diagnosis?
- How well were the following described and explained by the local diagnostic service during the diagnosis?
    - Diagnostic terms
    - Sources of support
    - Sources of information
    - Coping strategies
    - Future consequences
    - Sources of treatment
- Comments or recommendations about the service

Section 'C' rated the usefulness of sources of information on a Likert scale ranging from "1-not at all", "2-somewhat", "3-neutral/unable to judge", "4-useful", "5-extremely". Sources in this section included:

- Speech and language therapist
- Educational psychologist
- Books
- School teacher
- Local parents and support groups
- Consultant pediatrician
- Internet
- Newspapers/ Magazines
- Clinical Psychologist
- Local workshops/ Conferences
- Occupational therapist
- Family and friends
- General Practitioner
- Recommendations for other sources of information

Section 'D' rated the usefulness of support/treatment on a Likert scale ranging from "1-not at all", "2-somewhat", "3-neutral/unable to judge", "4-useful", "5-extremely". Support and treatment included in this section involved:

- Speech & language therapy
- Support at mainstream school
- Occupational therapy
- Change in diet
- Behaviour management or parent training
- Medications
- Recommendations for other sources of support and treatment

**Section 'E'** rated the useful and difficult features of the diagnosis on a Likert scale ranging from "1-strongly disagree", "2-disagree", "3-neutral", "4-agree", "5-strongly agree". Features of the diagnosis included:

- I was relieved that a diagnosis had been made
- I have a better understanding of my child's behaviour
- I have been able to accept my child's behaviour
- We have been able to adapt family life to my child's behaviour
- I have been able to get practical help for my child
- Other people have a better understanding of my child's behaviour
- It helped me stop blaming myself
- I have been able to get support for myself
- I have become more worried about my child's future
- Other people do not understand the diagnosis
- It is difficult to know which problem behaviours are caused by the disorder and which are not
- I was shocked by the diagnosis
- Diagnosing my child has been financially exhausting

**Section 'F'** rated parents' attitudes towards their children's diagnosis on a Likert scale ranging from "1-strongly disagree", "2-disagree", "3-neutral", "4-agree", "5-strongly agree". Attitudes stated included:

- Reactions to the diagnosis
  - We were shocked/upset devastated
  - The diagnosis confirmed our feelings
  - The diagnosis helped explain our child's behaviour
  - We were angry about the diagnosis
  - We welcomed the diagnosis
  - It is difficult to seek support before getting the diagnosis
  - Waiting for the diagnosis was stressful
  - Fortunately, we had started seeking support before the diagnosis
  - Getting my child diagnosed has been worth the financial burden

- Changes in attitude and experience over time
  - Our attitudes to the diagnosis have not changed over time
  - Our child has made good progress
  - It takes several years to come to term with diagnosis
  - The label has allowed us to access useful resources
  - The label allowed us to meet other families
  - A vague 'grey-area' diagnosis makes it very difficult to receive help
  - The increase in public awareness has helped

- Present conclusions about the diagnosis and the future
  - We wish that our child had been diagnosed earlier
  - We have become more accepting of the diagnosis
  - The label has been a good thing
  - We are unsure whether the diagnosis is correct
  - We have become more aware of the lack of resources of our child
  - We know there will be difficulties ahead
  - We are still upset and concerned about the diagnosis
  - There is less help available for children with special needs and disabilities as they get older
  - I feel isolated
  - The society is there for me
  - We were lucky that our child was diagnosed early on

## 3.5.2 Interviews

> The use of the interview in research marks a move away from seeing human subjects as simply manipulable and data as somehow external to individuals, and towards regarding knowledge as generated between humans, often through conversations.
>
> (Kvale, 1996 in Cohen, Manion & Morrison, 2000, p.267)

Interviews are a significant interchange of views between people on a topic of mutual interest focusing on the centrality of human interaction for knowledge production.

Boudah highlights the importance of interviews in qualitative research and views it as an opportunity for the researcher to get information about beliefs, perspectives, and views from the participant. A major advantage of interviews is its adaptability and the following up of ideas, probing responses and investigating motives and feelings that questionnaires can never do (Bell, 2010).

Even though conducting interviews is time-consuming and is considered a highly subjective technique, the researcher felt it was imperative to combine information from participants and integrate it with statistics derived from the questionnaire. Bell emphasizes that interviews can yield rich material and "often put flesh on the bones of questionnaire responses" (2010, p.161).

The researcher established a framework by selecting topics on which the interview should be guided. This method of guided or focused interviews allowed a considerable degree of latitude within the framework. Certain questions were asked, but respondents were given the freedom to talk about the topic and share their views in their own time. Focused interviews greatly simplify recording and analysis since the framework is formerly established (Bell, 2010).

The interviews were held at the school where the participants worked and at the time of their convenience, except for one interview with Mrs. Katie that was conducted via telephone. All interviews were completed in a span of 20 to 30 minutes. The participants all work closely with young children of all abilities in an inclusive educational setting and have extensive experience and knowledge with dealing with children and their parents. The questions used were standardized and open-ended since the exact wording and sequence of questions were predetermined. These semi-structured interviews involved asking a series of structured questions and then probed more deeply with open-form questions to obtain additional information (Gall, Gall & Borg, 2007). All the interviews were guided through the same basic questions in the same order. Participants were briefed about the nature of the study, and were guaranteed complete anonymity and confidentiality. The following questions were employed in the interview to guide it to its main purpose and assist in remaining on track.

- How do parents react when informed that their young child may require assessment due to concerns from the school or nursery?

- How do they feel about children being assessed?

- Do you feel that there are enough options in Dubai for parents seeking diagnosis/assessments for their children?

- What is your view regarding the costs of being diagnosed/assessed in Dubai?

- Are the reports reliable?

- Do you believe that interventions/therapies are effective in producing the required results?

- How does early intervention affect the child's future in academics?

- Is there any specific incident or situation you would like to share that could shed light to the diagnostic situation in Dubai?

- From your experience, what can parents do to ensure a bright future for their children diagnosed with special educational needs or disabilities here in Dubai?

Comparability of responses increased by having all respondents answer the same questions. Also, the researcher ensured that data was complete for each person on the topic addressed. This type of interview facilitates organization and analysis of data gathered (Cohen, Manion & Morrison, 2000).

Two group interviews were conducted in order to allow potential discussions to develop and thus yield a wide range of responses. Group interviews involve addressing questions to a group of individuals who have been assembled for this specific reason (Gall, Gall & Borg, 2007). These individuals have been selected because they are well informed about the research topic. Watts and Ebbutt explain that such interviews are especially useful when a group of people have been working together for a certain time and for a common purpose (1987 in Cohen, Manion & Morrison, 2000).

Group interviews can generate a wider range of responses than in individual interviews and can be useful for gaining insight into what might be pursued in subsequent individual interviews (p.287). Researchers believe that interactions among the participants stimulate them to state feelings, perceptions, and beliefs that they may not express if interviewed individually (Gall, Gall & Borg, 2007). Group interviews are also known as focus groups and are favored since they avoid putting the interviewer in a directive role. Questions were asked to initiate discussion, and then participants were allowed take major responsibility for stating their views and drawing out the views of others in the group.

These interviews were less time-consuming than the individual ones conducted and hence involved minimal disruption.

## 3.6 Data Analysis

The questionnaire conducted was developed using Survey Monkey Inc., an online software package that helps researchers design, administer and process questionnaires. Having the questionnaire solely onscreen allowed for rapid response entry, and thus data was examined automatically, producing graphs and tables, as well as a wide range of statistics.

The data collected from the semi-structured interviews were analyzed, summarized, and explained through Colaizzi's phenomenological data analysis approach (Sanders, 2003). The interviews were transcribed and significant statements were extracted from the interviews. Meanings were then formulated and clustered to emergent themes. The findings were then summarized into short and clear statements that the participants were able to validate.

## 3.7 Quality Indicators of the Research

When commencing the study, the researcher considered any and all personal and professional information that may affect data collection, analysis, and interpretation in the minds of the users of the finding, whether negative or positive. The researcher ensured that views were collected from multiple perspectives and over a reasonable amount of time. Since data collected from interviews is inevitably interpretive, the analysis was less of an accurate representation and more of a reflexive, reactive interaction between the researcher and the decontextualized data that were already interpretations of a social encounter (Cohen, Manion, & Morrison, 2000). The several stages in analysis included:

- Generating natural statements and meanings
- Classifying, categorizing, and ordering these statements and meanings
- Structuring narratives to describe the interview contents
- Interpreting the interview data (p.282)

Finally, asking interview participants to verify the accuracy of the findings further ensured the credibility of the study.

## 3.8 Ethical Considerations

From the commencement of the study and throughout, the researcher respected all ethical considerations with regards to conducting and operating the research. Questionnaires are known to be an intrusion into the life of respondents, be it in terms of time taken to complete the questionnaire, the level of sensitivity of the questions, or the possible invasion of privacy (Cohen, Manion, & Morrison, 2000). But for this study, parents who responded to the questionnaire did so completely voluntarily and were not coerced whatsoever into completing it. Many participants skipped questions and even withdrew midway through answering the questionnaire. Creswell stresses the rights of participants in any survey by stating that "(b)efore participating in any research, individuals need to know the purpose and aims of the study, how the results will be used, and the likely social consequences the study will have on their lives" (2008, p.12). When they participate and provide information, their anonymity is protected and guaranteed by the researcher.

Confidentiality, anonymity and non-traceability were clearly noted and explained before participants commenced participation in either research tool. Interviews are also identified to have an ethical dimension concerning interpersonal interaction that produces information about the human condition (Cohen, Manion, & Morrison, 2000). Therefore, the researcher was aware and acted upon the three main ethical issues that include consent, confidentiality, and consequences of the interviews (Kvale, 1996: 111-20 in Cohen, Manion, & Morrison, 2000).

## 3.9 Challenges and Limitations

As a former teacher in the school where part of the research was conducted, the researcher was confronted with both a challenge and an advantage. The researcher had to deal with issues of bias, but on another note, being familiar with the staff allowed them to be at ease and provide genuine responses. The researcher was well informed of the school

policies and procedures taken with accounts to young children with SEND. The researcher was also aware of the objectivity challenge in choosing certain research methods and analyzing the findings, but triangulation was extensively used to crosscheck the data.

One of the limitations of this research is that it dealt with only one school and nursery in Dubai and thereby does not attempt to generalize the findings on other schools. A thorough large-scope research that involves many schools is recommended to capture a better picture of how the attitudes of parents of children with SEND towards diagnosis and early intervention affect children's future academic performance. Another limitation is manifested by the absence of UAE-based research regarding children with SEND being available to the public.

Although access to the school was relatively easy to arrange, the organization of interviews was not so. Coordinators, teachers and learning support staff juggled a busy schedule and convincing them to give up their break times was a bit of a challenge.

A challenge the researcher faced with regards to the questionnaire was to get a large number of responses from parents of children with SEND. Even though hundreds of questionnaires were sent out to diagnostic clinics, intervention centers, schools and even through social media, the researcher only received 25 responses. Unfortunately, out of the 25 responses, only 5 were complete. This could be due to the language factor since another limitation of the study was that the questionnaire was administered in English only. This resulted in many Arabic-speaking parents not being able to respond adequately to the questions and therefore withdrawing prior or mid-questionnaire.

Furthermore, the study of any school practice would deem incomplete without the students' perception. SEND students are the primary recipients of the services and have every right to voice their opinions and thoughts. Also, observation of students who received early intervention as opposed to those who did not would have provided insightful information to the research. However, due to the time and word count limitations, the research did not include these segments.

# Chapter Four

## FINDINGS

This study was conducted through the use of several tools to gain a thorough understanding of parents' attitudes towards diagnosis and intervention in Dubai and how that may affect children's future in academic performance. The research findings of the questionnaire and the interviews are presented below.

## 4.1 Questionnaire Findings

The first part of the questionnaire focused on demographic details including the sex of the child with SEND, current age of the child, age of diagnosis, the diagnosis, person participating in the survey, and that person's educational background. Results are as follows:

**Q.1 Sex of the child** (25 answered, 0 skipped)
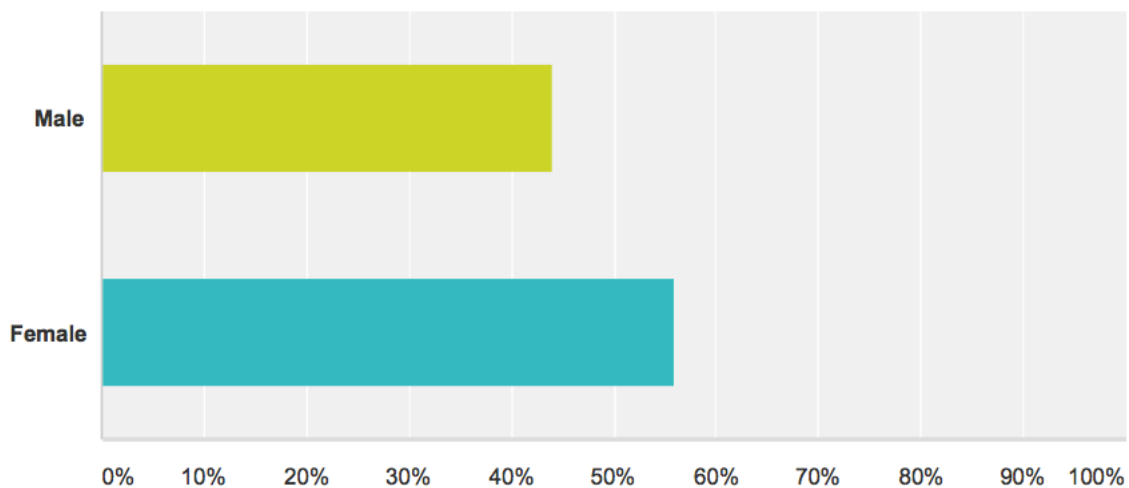


Figure 1.1: Questionnaire response graph – Q.1

**Q.2 Current age of the child** (25 answered, 0 skipped)

Answers ranged from 5 months up to 25 years.

| # | Responses | Date |
|---|---|---|
| 1 | 4 | 12/13/2016 9:44 AM |
| 2 | 5 months | 12/11/2016 10:07 PM |
| 3 | 7 | 12/11/2016 10:00 PM |
| 4 | 7 months 13 days | 12/9/2016 12:29 AM |
| 5 | 7 | 12/8/2016 6:41 PM |
| 6 | 6 | 12/8/2016 5:16 PM |
| 7 | 5 | 12/6/2016 9:24 PM |
| 8 | 6 | 12/5/2016 5:57 PM |
| 9 | 17 months | 12/5/2016 1:30 PM |
| 10 | 5 | 12/5/2016 12:52 PM |
| 11 | 4.9 | 12/4/2016 5:16 PM |
| 12 | 5 | 12/4/2016 4:43 PM |
| 13 | 1 | 12/4/2016 3:21 PM |
| 14 | 4 | 12/4/2016 3:14 PM |
| 15 | 11 month | 12/4/2016 2:44 PM |
| 16 | 7 | 12/4/2016 2:22 PM |
| 17 | 13-5-2016 | 12/4/2016 2:06 PM |
| 18 | 9 | 12/4/2016 11:11 AM |
| 19 | 7 | 12/4/2016 10:53 AM |
| 20 | 25 | 11/25/2016 3:06 PM |
| 21 | Six | 11/25/2016 1:17 AM |
| 22 | 5 years and 9 monthes | 11/25/2016 1:07 AM |
| 23 | 3 | 11/24/2016 2:14 PM |
| 24 | 19 | 11/24/2016 1:17 PM |
| 25 | 12 | 11/24/2016 12:52 PM |

Table 2.1: Questionnaire response list – Q.2

**Q.3 Age of the diagnosis** (25 answered, 0 skipped)
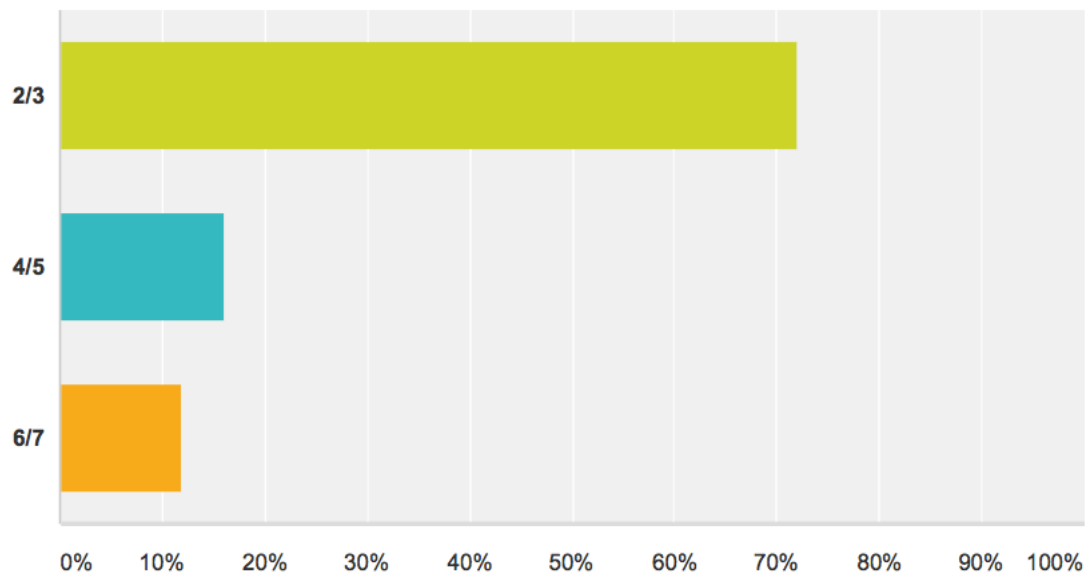


Figure 1.2: Questionnaire response graph – Q.3

**Q.4 Diagnosis** (25 answered, 0 skipped)

Responses included 13 cases of Down Syndrome (DS), 5 cases of Autism Spectrum Disorder (ASD), 1 case of Proximal Femoral Focal Deficiency (PFFD), 1 case of speech delay, 1 unspecified genetic condition, and 1 unspecified physical impairment.

| # | Responses | Date |
|---|---|---|
| 1 | اعاقة حركيه | 12/13/2016 9:44 AM |
| 2 | Down syndrome + hypotonia | 12/11/2016 10:07 PM |
| 3 | Down syndrome | 12/11/2016 10:00 PM |
| 4 | Down Syndrome | 12/9/2016 12:29 AM |
| 5 | 6/7 | 12/8/2016 6:41 PM |
| 6 | Down syndrome | 12/8/2016 5:16 PM |
| 7 | Autism | 12/6/2016 9:24 PM |
| 8 | PFFD | 12/5/2016 5:57 PM |
| 9 | DS | 12/5/2016 1:30 PM |
| 10 | Autism | 12/5/2016 12:52 PM |
| 11 | Genatic | 12/4/2016 5:16 PM |
| 12 | Autism | 12/4/2016 4:43 PM |
| 13 | Down sendrom | 12/4/2016 3:21 PM |
| 14 | Speech delay | 12/4/2016 3:14 PM |
| 15 | Down syndrome | 12/4/2016 2:44 PM |
| 16 | Normal | 12/4/2016 2:22 PM |
| 17 | 6month | 12/4/2016 2:06 PM |
| 18 | Autism | 12/4/2016 11:11 AM |
| 19 | ASD | 12/4/2016 10:53 AM |
| 20 | Down Syndrome | 11/25/2016 3:06 PM |
| 21 | Down syndrome | 11/25/2016 1:17 AM |
| 22 | Diwn syndrom | 11/25/2016 1:07 AM |
| 23 | down syndrome | 11/24/2016 2:14 PM |
| 24 | Down Syndrome | 11/24/2016 1:17 PM |
| 25 | Down syndrom | 11/24/2016 12:52 PM |

Table 2.2: Questionnaire response list – Q.4

**Q.5 Who is completing the survey**  (25 answered, 0 skipped)
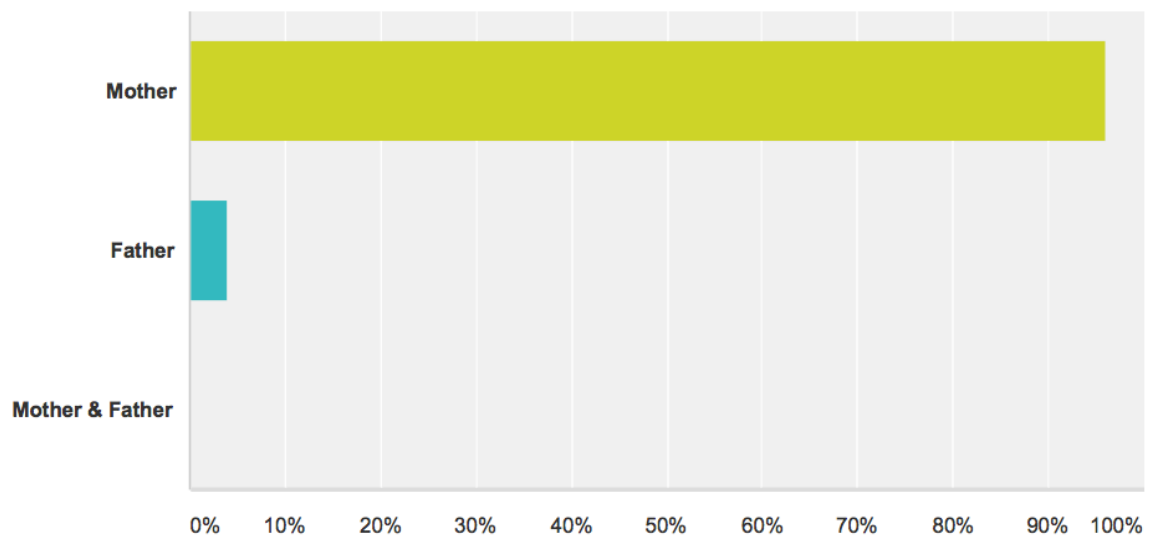
Figure 1.3: Questionnaire response graph – Q.5

**Q.6 Educational Background of person completing the survey**

(25 answered, 0 skipped)
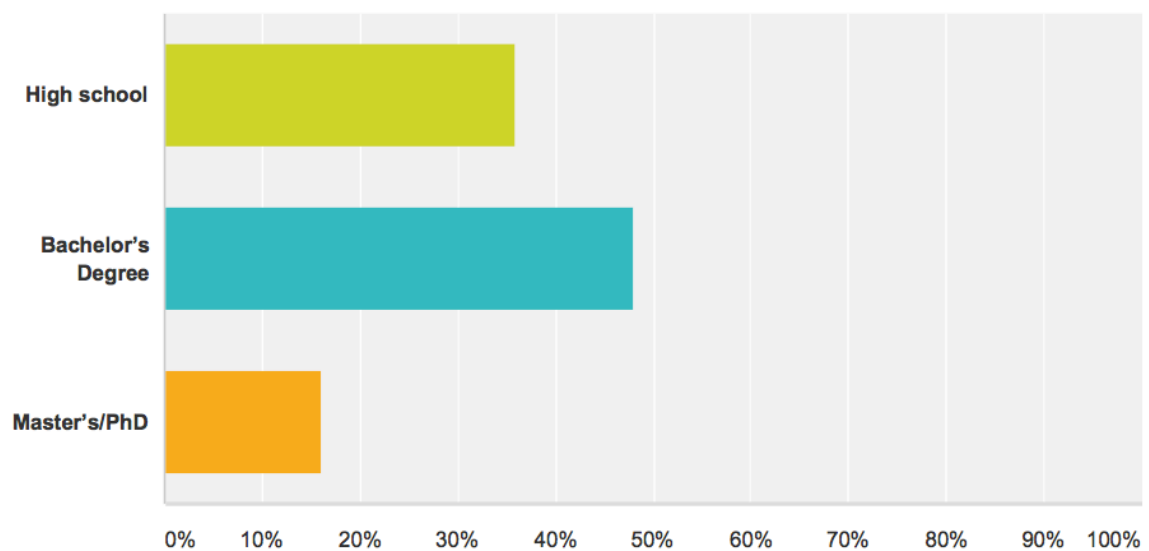
Figure 1.4: Questionnaire response graph – Q.6

**Q.7 How sensitive were the local diagnostic service team in giving the diagnosis?**

(16 answered, 9 skipped)

| Not at all | Somewhat | Neutral/Unable to Judge | Moderately | Extremely | Total |
|---|---|---|---|---|---|
| 12.50% | 25.00% | 12.50% | 37.50% | 12.50% | |
| 2 | 4 | 2 | 6 | 2 | 16 |

Table 2.3: Questionnaire response rate – Q.7

**Q.8 How well were the following described and explained by the local diagnostic service during the diagnosis?**

(16 answered, 9 skipped)

| | Not at all | Somewhat | Neutral/Unable to Judge | Moderately | Extremely | Total |
|---|---|---|---|---|---|---|
| Diagnostic terms | 25.00% | 25.00% | 0.00% | 31.25% | 18.75% | |
| | 4 | 4 | 0 | 5 | 3 | 16 |
| Sources of support | 13.33% | 40.00% | 13.33% | 20.00% | 13.33% | |
| | 2 | 6 | 2 | 3 | 2 | 15 |
| Sources of information | 20.00% | 26.67% | 20.00% | 20.00% | 13.33% | |
| | 3 | 4 | 3 | 3 | 2 | 15 |
| Coping strategies | 26.67% | 20.00% | 26.67% | 13.33% | 13.33% | |
| | 4 | 3 | 4 | 2 | 2 | 15 |
| Future consequences | 20.00% | 26.67% | 13.33% | 20.00% | 20.00% | |
| | 3 | 4 | 2 | 3 | 3 | 15 |
| Sources of treatment | 6.67% | 33.33% | 26.67% | 20.00% | 13.33% | |
| | 1 | 5 | 4 | 3 | 2 | 15 |

Table 2.4: Questionnaire response rate – Q.8

**Q.9 How useful were the following sources of information with regards to your child's diagnosis?**

(10 answered, 15 skipped)

| | Not at all | Somewhat | Neutral/Unable to judge | Useful | Extremely Useful | Total | Weighted Average |
|---|---|---|---|---|---|---|---|
| Speech and language therapist | 22.22%<br>2 | 22.22%<br>2 | 22.22%<br>2 | 22.22%<br>2 | 11.11%<br>1 | 9 | 2.78 |
| Educational psychologist | 11.11%<br>1 | 11.11%<br>1 | 33.33%<br>3 | 33.33%<br>3 | 11.11%<br>1 | 9 | 3.22 |
| Books | 33.33%<br>3 | 0.00%<br>0 | 22.22%<br>2 | 22.22%<br>2 | 22.22%<br>2 | 9 | 3.00 |
| School teacher | 10.00%<br>1 | 10.00%<br>1 | 30.00%<br>3 | 30.00%<br>3 | 20.00%<br>2 | 10 | 3.40 |
| Local parents and support groups | 10.00%<br>1 | 10.00%<br>1 | 30.00%<br>3 | 40.00%<br>4 | 10.00%<br>1 | 10 | 3.30 |
| Consultant paediatrician | 11.11%<br>1 | 22.22%<br>2 | 11.11%<br>1 | 44.44%<br>4 | 11.11%<br>1 | 9 | 3.22 |
| Internet | 0.00%<br>0 | 0.00%<br>0 | 0.00%<br>0 | 66.67%<br>6 | 33.33%<br>3 | 9 | 4.33 |
| Newspapers/ Magazines | 44.44%<br>4 | 33.33%<br>3 | 0.00%<br>0 | 11.11%<br>1 | 11.11%<br>1 | 9 | 2.11 |
| Clinical Psychologist | 40.00%<br>4 | 20.00%<br>2 | 20.00%<br>2 | 10.00%<br>1 | 10.00%<br>1 | 10 | 2.30 |
| Local workshops/ Conferences | 30.00%<br>3 | 10.00%<br>1 | 40.00%<br>4 | 10.00%<br>1 | 10.00%<br>1 | 10 | 2.60 |
| Occupational therapist | 33.33%<br>3 | 11.11%<br>1 | 11.11%<br>1 | 33.33%<br>3 | 11.11%<br>1 | 9 | 2.78 |
| Family and friends | 11.11%<br>1 | 22.22%<br>2 | 11.11%<br>1 | 33.33%<br>3 | 22.22%<br>2 | 9 | 3.33 |
| General Practitioner | 33.33%<br>3 | 22.22%<br>2 | 22.22%<br>2 | 11.11%<br>1 | 11.11%<br>1 | 9 | 2.44 |

Table 2.5: Questionnaire response rate – Q.9

**Q.10 How useful were the following support/treatments?**

(9 answered, 16 skipped)

| | Not at all | Somewhat | Neutral/Unable to judge | Useful | Extremely useful | Total | Weighted Average |
|---|---|---|---|---|---|---|---|
| Speech & Language therapy | 0.00%<br>0 | 11.11%<br>1 | 11.11%<br>1 | 66.67%<br>6 | 11.11%<br>1 | 9 | 3.78 |
| Support at mainstream school | 0.00%<br>0 | 22.22%<br>2 | 33.33%<br>3 | 33.33%<br>3 | 11.11%<br>1 | 9 | 3.33 |
| Occupational therapy | 0.00%<br>0 | 0.00%<br>0 | 33.33%<br>3 | 55.56%<br>5 | 11.11%<br>1 | 9 | 3.78 |
| Change in diet | 22.22%<br>2 | 11.11%<br>1 | 33.33%<br>3 | 22.22%<br>2 | 11.11%<br>1 | 9 | 2.89 |
| Behaviour management or parent training | 0.00%<br>0 | 22.22%<br>2 | 33.33%<br>3 | 22.22%<br>2 | 22.22%<br>2 | 9 | 3.44 |
| Medications | 11.11%<br>1 | 0.00%<br>0 | 55.56%<br>5 | 22.22%<br>2 | 11.11%<br>1 | 9 | 3.22 |

Table 2.6: Questionnaire response rate – Q.10

## Q.11 How relevant are the following features of the diagnosis?

(7 answered, 18 skipped)

| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree | Total | Weighted Average |
|---|---|---|---|---|---|---|---|
| I was relieved that a diagnosis had been made | 14.29%<br>1 | 14.29%<br>1 | 14.29%<br>1 | 28.57%<br>2 | 28.57%<br>2 | 7 | 3.43 |
| I have a better understanding of my child's behaviour | 0.00%<br>0 | 0.00%<br>0 | 14.29%<br>1 | 71.43%<br>5 | 14.29%<br>1 | 7 | 4.00 |
| I have been able to accept my child's behaviour | 0.00%<br>0 | 0.00%<br>0 | 14.29%<br>1 | 71.43%<br>5 | 14.29%<br>1 | 7 | 4.00 |
| We have been able to adapt family life to my child's behaviour | 0.00%<br>0 | 0.00%<br>0 | 28.57%<br>2 | 57.14%<br>4 | 14.29%<br>1 | 7 | 3.86 |
| I have been able to get practical help for my child | 0.00%<br>0 | 0.00%<br>0 | 28.57%<br>2 | 57.14%<br>4 | 14.29%<br>1 | 7 | 3.86 |
| Other people have a better understanding of my child's behaviour | 0.00%<br>0 | 42.86%<br>3 | 14.29%<br>1 | 28.57%<br>2 | 14.29%<br>1 | 7 | 3.14 |
| It helped me stop blaming myself | 0.00%<br>0 | 14.29%<br>1 | 0.00%<br>0 | 71.43%<br>5 | 14.29%<br>1 | 7 | 3.86 |
| I have been able to get support for myself | 0.00%<br>0 | 28.57%<br>2 | 0.00%<br>0 | 57.14%<br>4 | 14.29%<br>1 | 7 | 3.57 |
| I have become more worried about my child's future | 0.00%<br>0 | 0.00%<br>0 | 0.00%<br>0 | 85.71%<br>6 | 14.29%<br>1 | 7 | 4.14 |
| Other people do not understand the diagnosis | 0.00%<br>0 | 0.00%<br>0 | 14.29%<br>1 | 71.43%<br>5 | 14.29%<br>1 | 7 | 4.00 |
| It is difficult to know which problem behaviours are caused by the disorder and which are not | 0.00%<br>0 | 0.00%<br>0 | 14.29%<br>1 | 71.43%<br>5 | 14.29%<br>1 | 7 | 4.00 |
| I was shocked by the diagnosis | 0.00%<br>0 | 14.29%<br>1 | 0.00%<br>0 | 42.86%<br>3 | 42.86%<br>3 | 7 | 4.14 |
| Diagnosing my child has been financially exhausting | 0.00%<br>0 | 0.00%<br>0 | 0.00%<br>0 | 85.71%<br>6 | 14.29%<br>1 | 7 | 4.14 |

Table 2.7: Questionnaire response rate – Q.11

## Q.12 How was your reaction to the diagnosis?

(7 answered, 18 skipped)

| | Strongly disagree | Disagree | Neutral | Agree | Strongly Agree | Total |
|---|---|---|---|---|---|---|
| We were shocked/upset devastated | 0.00% 0 | 28.57% 2 | 0.00% 0 | 42.86% 3 | 28.57% 2 | 7 |
| The diagnosis confirmed our feelings | 0.00% 0 | 14.29% 1 | 0.00% 0 | 57.14% 4 | 28.57% 2 | 7 |
| The diagnosis helped explain our child's behaviour | 0.00% 0 | 0.00% 0 | 14.29% 1 | 71.43% 5 | 14.29% 1 | 7 |
| We were angry about the diagnosis | 0.00% 0 | 42.86% 3 | 14.29% 1 | 28.57% 2 | 14.29% 1 | 7 |
| We welcomed the diagnosis | 0.00% 0 | 14.29% 1 | 0.00% 0 | 71.43% 5 | 14.29% 1 | 7 |
| It is difficult to seek support before getting the diagnosis | 0.00% 0 | 14.29% 1 | 28.57% 2 | 28.57% 2 | 28.57% 2 | 7 |
| Waiting for the diagnosis was stressful | 0.00% 0 | 0.00% 0 | 14.29% 1 | 57.14% 4 | 28.57% 2 | 7 |
| Fortunately, we had started seeking support before the diagnosis | 0.00% 0 | 14.29% 1 | 0.00% 0 | 28.57% 2 | 57.14% 4 | 7 |
| Getting my child diagnosed has been worth the financial burden | 0.00% 0 | 14.29% 1 | 42.86% 3 | 28.57% 2 | 14.29% 1 | 7 |

Table 2.8: Questionnaire response rate – Q.12

## Q.13 Changes in attitude and experience over time

(6 answered, 19 skipped)

| | Srongly Disagree | Disagree | Neutral | Agree | Strongly Disagree | Total |
|---|---|---|---|---|---|---|
| Our attitudes to the diagnosis have not changed over time | 16.67% 1 | 33.33% 2 | 0.00% 0 | 33.33% 2 | 16.67% 1 | 6 |
| Our child has made good progress | 0.00% 0 | 16.67% 1 | 0.00% 0 | 66.67% 4 | 16.67% 1 | 6 |
| It takes several years to come to term with diagnosis | 16.67% 1 | 0.00% 0 | 16.67% 1 | 50.00% 3 | 16.67% 1 | 6 |
| The label has allowed us to access useful resources | 0.00% 0 | 0.00% 0 | 33.33% 2 | 50.00% 3 | 16.67% 1 | 6 |
| The label allowed us to meet other families | 0.00% 0 | 0.00% 0 | 0.00% 0 | 83.33% 5 | 16.67% 1 | 6 |
| A vague 'grey-area' diagnosis makes it very difficult to receive help | 0.00% 0 | 0.00% 0 | 50.00% 3 | 33.33% 2 | 16.67% 1 | 6 |
| The increase in public awareness has helped | 0.00% 0 | 0.00% 0 | 16.67% 1 | 66.67% 4 | 16.67% 1 | 6 |

Table 2.9: Questionnaire response rate – Q.13

**Q.14 Present conclusions about the diagnosis and the future**

(5 answered, 20 skipped)

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree | Total |
|---|---|---|---|---|---|---|
| We wish that our child had been diagnosed earlier | 0.00%<br>0 | 20.00%<br>1 | 20.00%<br>1 | 20.00%<br>1 | 40.00%<br>2 | 5 |
| We have become more accepting of the diagnosis | 0.00%<br>0 | 0.00%<br>0 | 20.00%<br>1 | 40.00%<br>2 | 40.00%<br>2 | 5 |
| The label has been a good thing | 0.00%<br>0 | 20.00%<br>1 | 40.00%<br>2 | 20.00%<br>1 | 20.00%<br>1 | 5 |
| We are unsure whether the diagnosis is correct | 0.00%<br>0 | 40.00%<br>2 | 20.00%<br>1 | 20.00%<br>1 | 20.00%<br>1 | 5 |
| We have become more aware of the lack of resources of our child | 0.00%<br>0 | 0.00%<br>0 | 40.00%<br>2 | 40.00%<br>2 | 20.00%<br>1 | 5 |
| We know there will be difficulties ahead | 0.00%<br>0 | 0.00%<br>0 | 0.00%<br>0 | 80.00%<br>4 | 20.00%<br>1 | 5 |
| We are still upset and concerned about the diagnosis | 0.00%<br>0 | 20.00%<br>1 | 20.00%<br>1 | 40.00%<br>2 | 20.00%<br>1 | 5 |
| There is less help available for children with special needs and disabilities as they get older | 0.00%<br>0 | 0.00%<br>0 | 0.00%<br>0 | 80.00%<br>4 | 20.00%<br>1 | 5 |
| I feel isolated | 20.00%<br>1 | 0.00%<br>0 | 40.00%<br>2 | 20.00%<br>1 | 20.00%<br>1 | 5 |
| The society is there for me | 0.00%<br>0 | 20.00%<br>1 | 20.00%<br>1 | 20.00%<br>1 | 40.00%<br>2 | 5 |
| We were lucky that our child was diagnosed early on | 0.00%<br>0 | 0.00%<br>0 | 40.00%<br>2 | 20.00%<br>1 | 40.00%<br>2 | 5 |

Table 2.10: Questionnaire response rate – Q.14

## 4.2 Interview Findings

This section presents findings extracted from individual and group interviews held with various members working in the education industry. All participants were briefed about the research prior to the interviews. The educational purpose and techniques of the study were explained and interviewees were guaranteed complete anonymity and confidentiality. Thereby, all names mentioned are pseudonyms, but their professional statuses and experiences are authentic.

Three main themes were extracted from the interview data (refer to Appendix 4) and quotes were used in the body of the themes in order to provide a clear and honest image of the perceptions. These themes consist of:

1) The reaction and feelings of parents towards assessment and diagnosis,

2) The financial costs and reliability of diagnosis and intervention, and

3) The benefits of early intervention and its results.

## 4.2.1 Theme 1: Parents' reactions and feelings towards assessment

Most of the participants agreed that the initial reaction of parents when they were informed that their child might need assessment was complete denial, followed by feelings of anxiousness, fear, and reluctance.

*"Complete denial! They see that their kids are normal at home. Some parents are even doctors and they still deny our concerns. Around 80% of our parents react that way."* (Mona – Nursery Manager)

*"Most parents are in denial. I have to prove to them my concerns… sometimes we show parents videos of concerned behaviours, even though we know its not allowed, but we need to convince them."* (Amy – Team Leader & Nursery Teacher)

*"They feel worried and shocked. Some live in denial as no parent would wish for their child to be different. They feel their child would be neglected or looked down upon if their child gets assessed. Parents many times feel that the school treats their children differently or that the school is targeting their child. Very few parents understand that the assessment could help their child further on."* (Rosalinda – FS Class Teacher)

*"Parents at the first stage are in denial, there is a blame game, the school is also targeted and finally when they understand in the 3$^{rd}$ or 4$^{th}$ meeting that its for their child's betterment, they agree for an assessment."* (Ameera – FS Learning Support)

*"I noticed that their first reaction is being anxious and having the fear of the unknown, because they don't know what will be the result of the assessment or why they even have to go for the assessment."* (Katie – ABA Therapist)

*"Defensive…angry!"* (Deepti – Former Nursery & FS SENCO)

*"It varies really…with first borns, new parents have nothing to compare their child's behaviour to. It's easier if they have siblings and it really depends on the parents'*

*sensitivity, education, exposure and family history."* (Jane – School Counselor & Head of SEN)

*"Denial! It takes a long time to convince the parents that there is an issue. Assessment is the second step, and it usually takes us months to convince the parents."* (Sally – Nursery & FS SENCO)

Some reactions were so extreme that *"one couple decided to move their child to another nursery. But as we expected, the other nursery had similar concerns regarding their child"* (Mona – Nursery Manager). And another *"parent fainted, even though it was her fifth child, she didn't even notice that he was different. She was in complete shock."* (Amy – Team Leader & Nursery Teacher)

Alternatively, one nursery teacher thought that *"parents are very cooperative. Sometimes they are initially in denial, but it's not a big issue. They get over it quickly and want to know what they can do to help their child… it depends really, this year one parent was really responsive. The previous years, some parents would take their kids out of the nursery and put them somewhere else."* (Noor – Nursery Teacher)

Mona, the nursery manager, recalled a parent *"who is well-educated, and she noticed something different about her third child. She actually approached us and asked for the SENCO to observe her daughter. Her daughter was later diagnosed with ASD."*

*"Some parents are open-minded enough to accept their child will need to have an assessment."* (Katie – ABA Therapist)

*"With severe cases, the parents understand and their attitudes are more positive because it shows. But in certain cases where early intervention is required, the signs are not too obvious."* (Jane – School Counselor & Head of SEN)

As one FS teacher sums it, parents generally have *"mixed feelings of reluctance, fear, and anxiety… they are scared and reluctant to accept that there might be something wrong."* (Priya)

## 4.2.2 Theme 2: Financial costs and reliability of diagnosis and intervention

Most participants agreed that having children assessed and diagnosed with SEND is a huge financial burden, especially for families with average income.

*"Some parents refuse to assess because of financial costs. Once, a grandparent came in with concerns regarding her grandkid, but after she found out they had to pay for a shadow teacher if the child was diagnosed… she refused. Many parents self-educate themselves to try to cut down costs of therapies. Unfortunately, schools do not allow parents to become their children's shadow teacher in class. This is another financial burden parents must endure."* (Mona – Nursery Manager)

*"There are options for parents, but they are unreasonable. These centers are too expensive, and after their child is diagnosed, they still have to pay for a shadow teacher in the nursery and school. These parents are middle-classed families, how can they afford all these expenses?"* (Amy – Team Leader & Nursery Teacher)

*"I feel it's expensive. If it was a matter of one time it's still alright, but I guess these assessment procedures are repeated every two years, which is taxing for the parents mentally as well as financially."* (Priya – FS Class Teacher)

*"They are pretty expensive. The common man is not considered. Children who are from poor or low-scale families are left to suffer because there are no measures put in place for them and their families."* (Rosalinda – FS Class Teacher)

*" The assessments and the follow-ups are very expensive, as a result, many parents choose not to go ahead… as they cannot bear the costs."* (Ameera – FS Learning Support)

*"Honestly, I believe it is indeed expensive."* (Katie – ABA Therapist)

*"There are…financial constraints because the price of assessments and diagnosing is very high. We do have a list of small centers as well, but still there are the costs of therapies and follow-ups…. If the child has severe needs, they require a shadow teacher and many parents can't afford that too."* (Golnar – FS Learning Support)

*"Some institutes provide free assessments for locals, but the packages for expatriates range from 10 to 15 thousand a month, which is inhumane. Also, many parents complain that there are waiting lists in the center that will assess their child, and some even wait for 2 months before the diagnosis."* (Sally – Nursery & FS SENCO)

Only one nursery teacher believed that *"the costs are average. Around 7,000 Dirhams for a complete psychoanalysis excluding speech assessment."* (Noor – Nursery Teacher)

With regards to report reliability, there were mixed opinions. Class teachers generally had positive attitudes towards reports received, but the counselor, SENCO and learning support staff were not too satisfied.

*"I don't know if the reports are reliable. I haven't seen any!"* (Amy – Team Leader & Nursery Teacher)

*"Yes, the reports are reliable."* (Noor – Nursery Teacher)

*"I am sure they are."* (Priya – FS Class Teacher)

*"Sometimes the reports are reliable, but you might still need to get a second opinion."* (Rosalinda – FS Class Teacher)

*"In my opinion, I believe the results are reliable since the physicians or psychologists doing the assessment are the experts in their own field, they have studied for so many years and gained a lot of experience. They are all professionals."* (Katie – ABA Therapist)

*"...through experience, I've understood there are a lot of centers but few give genuine reports."* (Ameera – FS Learning Support)

The school counselor and former Nursery & FS SENCO had a lot to say with regards to report reliability. They shared with us that *"centers are really making parents hesitate. Many of the reports are very unreliable; we got three inconsistent diagnoses for the same child from the same center. And it was a very reputable center. When we called them to clarify, they said that these parents are our clients, and they are entitled to get whatever they ask for.*

*Another student, we asked his parents for academic and behavioural referral. So the parents chose a psychiatrist recommended by the KHDA. We received an atrocious report where they used outdated diagnostic tools. He was a clinical psychologist.*

*Many of these reports are inconsistent, and it's very disappointing. They deprive the child of his right to get proper intervention.*" (Jane – School Counselor & Head of SEN)

*"So we really can't blame parents if they are hesitant to get their child assessed, after they hear of such cases especially. We get skimpy reports from affordable centers unfortunately. The school recommends to parents certain reliable centers, but not all parents can afford them."* (Deepti – Former Nursery & FS SENCO)

*"We recommend the centers that provide reliable results. Some reports are not very reliable to be honest, the battery of tests they use is very outdated and so we know the quality we receive from the clinic is not very good. We definitely don't recommend these centers or clinics."* (Sally – Nursery & FS SENCO)

### 4.2.3 Theme 3: Benefits of early intervention

All participants unanimously agreed that early intervention was undoubtedly beneficial for a child diagnosed with SEND, and many shared stories from their personal experience.

*"Early intervention is very effective for the child. We have witnessed how late intervention affects a child's future. Our colleague here enrolled her child in the nursery when he was 2 years old. We all noticed his odd behaviour, but she refused to accept our observations and did not take him for assessment. Later, when she travelled to Ireland, her son was diagnosed with ASD at the age of 5. She regretted not having diagnosed him earlier and was very upset at the lost opportunity.*

*Most of the children diagnosed with SEN are very intelligent academically. Their differences are in their social and behavioural traits. We usually have 10 cases of SEND each year out of 140 new enrollments."* (Mona - Nursery Manager)

*"Early intervention is a must – absolutely! At this age, they form habits and personalities. E's son is an example. She didn't accept that her son was different till he*

*turned 5. It was too late then, and she really regretted it… intervention must begin at the right time."* (Amy, Team Leader & Nursery Teacher)

*"I strongly agree to this, as these therapies yield benefits in academic achievements and behaviour of the child. It helps to include the child in the mainstream by providing them with the help they need (emotional, academic, etc.),"* (Priya, FS Class Teacher)

*"Yes, interventions and therapies are effective when followed up. Early intervention is the best thing that can happen to a child with SEND. It will help the parents have a more strategized way of catering for the child's developmental needs: academically, socially and medically. The child will benefit from sessions as the therapist will have planned measures which focus on the areas of concern."* (Rosalinda – FS Class Teacher)

*"Interventions give you a clear picture of the child's needs, abilities, and the areas where he is lacking. Thus intervention could give an insight into the child's needs and challenges. As development takes place at a very young age, early intervention helps understand the delays of these learning developments which otherwise would have hindered the child's further development."* (Ameera – FS Learning Support)

*"I definitely believe doing therapies and intervention help these wonderful children. I for example am a therapist and I have personally witnessed the improvement on the child when he started having therapies. I strongly suggest an early intervention be done to children who require therapies. The earlier the intervention done to them, the more positive the outcome will be expected. The child will have many possibilities for his future once an early intervention was made."* (Katie – ABA Therapist)

*"Intervention definitely helps, especially that many children can be wooed off the help later on… its either that or parents are washed out after the diagnosis and so rely on the school support solely. This isn't always enough for the child's requirements."* (Jane – School Counselor & Head of SEN)

*"We notice an overall improvement. Most of our students benefit mostly from ABA and speech therapy. We have a lot of high-functioning autistic students and we can see the gradual process with the support of intervention and therapies. Intervention is more effective at a younger age, therefore early intervention is very important. We have many students who had speech delay and now they are at par with the rest of the class thanks to*

*intervention. One of our students is now gifted in reading thanks to the efforts of parents and constant therapy.”* (Sally – Nursery & FS SENCO)

# Chapter Five

## ANALYSIS AND DISCUSSION

Findings from the questionnaire and the interviews provided an insight to parents' attitudes towards SEND diagnosis and intervention in Dubai. The interviews with educational specialists mainly shed light on how these attitudes affect children's future in education. Even though there were numerous challenges and limitations, a few themes were consistently projected across these various tools. With the simple statistics derived from the questionnaire, the researcher was able to describe phenomena, identify relationships, and explore reasons for these relationships; statistics "are remarkably helpful in giving simple summation of complex situations" (Check & Schutt, 2012, p.296).

In the questionnaire findings, 72% of the participants diagnosed their children between the ages of 2 and 3 years (refer to Figure 1.2). This appears to be a pleasant indicator of early diagnosis and thus early intervention, but it is also impartial to state that 64% of these cases were already identified at birth or even during pregnancy, such as DS and PFFD (refer to Table 2.1). 96% of the parents who volunteered to participate in the questionnaire were mothers and all of them received educational degrees ranging from high school degrees and diplomas to Master degrees and PhDs (refer to Figure 1.3 and 1.4). These degrees indicate the importance of education to the parents, which inevitably reflect how they view their children's education regardless of their child's condition.

50% of the parents agreed that the local diagnostic service team were sensitive in giving the diagnosis, 12.5% were neutral while the remaining 37.5% disagreed (refer to Table 2.3). Over 50% of parents who responded also believed that various treatments and support systems were either very useful or useful in certain areas such as speech and language therapy, and occupational therapy. However, they did not seem very keen on support received from schools, the usefulness of diet change and medications (refer to Table 2.6). These percentages fairly signify a young and evolving support system in mainstream schools for children with SEND.

Almost 50% of parents who responded were relieved that their children were diagnosed early on and 85% felt that they had a better understanding and were able to accept their

children's behaviour due to the diagnosis. Nevertheless, all the parents were worried about their children's future and all of them unanimously agreed that diagnosing their children and getting them support has been financially exhausting (refer to Table 2.7). This finding seems to be in sync with the findings from the interviews as well, where 90% of the participants mentioned the extreme expenses parents endure in order to assess their children and provide them with support in Dubai. As Rosalinda stated during the interview,

…the common man is not considered… low-scale families are left to suffer. I have a family friend who's child suffers from speech and language delay… when she couldn't cope with the burden of paying high fees, she had to send him back home while herself and her children remain here. This is really sad. At least children who are born here should have some sort of medical and academic benefits or privileges. (refer to Appendix 4.5)

The school counselor and head of SEN even proposed that parents should do their research and try and work with their children at home in order to reduce therapy sessions (refer to Appendix 4.8). The Nursery and FS SENCO noted that there were some institutes that provide free assessments for locals, but for expatriates, assessment and intervention packages "range from 10 to 15 thousand a month, which is inhumane" (refer to Appendix 4.9). And since expats are already expected to pay for their children's education in Dubai, having children with SEND eventually becomes emotionally, socially, and financially overwhelming.

Over 80% of parents were happy with their children's progress over time though. All of them agreed that having their child labeled with SEND allowed them to meet other families with similar circumstances (refer to Table 2.10). Social support is essential for physical and mental health and well-being of children with SEND and their families. Evidence indicates that social and peer support is particularly important and beneficial for the well-being of those who care for children with chronic illness or disability in improving personal well-being and influencing parent-child play opportunities and child behaviour and development positively (Hammarberg et al., 2014).

The main concern however, after the children were assessed and provided with adequate and appropriate support, is what lies ahead for them when they grow older. 80% of parents who responded agreed and 20% strongly agreed that there will be difficulties ahead and that there is less help available for children with special needs and disabilities

as they get older (refer to Table 2.10). The Nursery and FS SENCO agrees with these parents and noted in her interview that "there is sadly no vocational setting in Dubai. Once students with SEN graduate from high school, there isn't much for them to do" (refer to Appendix 4.9).

The main purpose of the interviews was to understand how parents' attitudes affected their children's performance in the academic setting. All the participants agreed that early intervention yielded positive benefits in academic achievements and behaviours. Many even shared stories of parents who delayed diagnosis and intervention and their extreme regret in doing so. Ameera, a learning support in a Dubai based private school shared how the school "works closely with an intervention center. When they refer a child to their center (they) always get descriptive assessments and next steps and recommendations as what the school and home can do to help the child further" (refer to Appendix 4.6). Ameera also states the important role parents play in their children's learning; "they are the primary source of overcoming any learning difficulty or challenge the child may face" (refer to Appendix 4.6). She mentions that in order to empower a child, parents need to be able to provide constant support.

Generally, development of young children with special needs is greatly enhanced by early intervention programs that provide classroom or home-based education and parent support (M.L. Anderson, 2008; C.T. Ramey & S.L. Ramey, 1998 in Trawick-Smith, 2014). Trawick-Smith stresses the importance of early identification of special needs since some studies suggest that if intervention programs start as early as infancy, children will show fewer delays in later years. A large number of studies prove remarkable improvement in motor and cognitive abilities even if the child has not begun intervention until preschool (Shonkoff et al., 1992 in Trawick-Smith, 2014). "Infants and toddlers who are at risk of intellectual delay may be provided with nutritional, educational, or family services that can greatly offset the damaging effects" (p.158). Therefore, it is never too late for intervention, and the earlier the better.

Attitudes of parents have a direct affect on parental involvement in schools, which is of vital importance in the case of students with special educational needs and disabilities. Cotton and Wikelund (2001) suggest that the most effective form of parent involvement for students with special needs is one that not only engages parents in working directly with children in school but also carries over into learning activities that can be conducted

at home.  Westwood (2013) proposes that all schools need to have a clear policy that encourages and supports teachers in a professional working partnership with parents. Logsdon points three main reasons where parent involvement is invaluable in schools:

1- "they have the most complete understanding of their child's physical, social, developmental, and family history;
2- they have been, and will continue to be, the main adults most deeply involved in the educational process;
3- parents can work more closely with their children than other adults can" (2012 in Westwood, 2013).

In particular, parents of students with SEND can provide information on the child's strengths, weaknesses and interest as well as their background information including the child's history and development. Parents may also share information on family factors that may affect the child's learning, and offer observational notes on whether certain strategies and methods of instruction are helping the child learn. Therefore, suggestions for change and improvement are based on their knowledge of their child (Westwood, 2013).

# Chapter Six

## CONCLUSION, RECOMMENDATIONS, & FUTURE RESEARCH

### 6.1 Conclusion

This study explored attitudes of parents of children with SEND towards diagnosis and intervention in Dubai through data gathered from questionnaires and interviews. Unfortunately, due to a low response rate from the questionnaire, the views may not fully represent those of all parents whose children were diagnosed in Dubai. Also, the survey used a local sample and so the responses may not generalize to other areas of the UAE where experiences with professional diagnosis may be very different. However, from the information received, mostly positive attitudes towards services provided from the diagnostic centers were portrayed, including therapies and various intervention tools. Two main themes stood out during the questionnaire data analysis, which primarily focused on the financial strains parents had to endure in order to receive a diagnosis for their child followed up by therapies and interventions, and secondary, anxiety regarding their children's future after they graduate from school and the fear of the unknown.

Interviews conducted mainly focused on the implication of parents' attitudes towards their children's future in education. Participants from the educational field shared their thoughts and experiences, and all of them stressed the importance of early diagnosis and intervention in order to ensure the best possible social, emotional, and intellectual development of the child. The main themes that stood out from these interviews also included the financial pressure that most parents suffered in order to diagnose their children and provide therapies and intervention, and which most frequent than not require parents to postpone sending their children to clinics and centers until later, and almost always, way too late. Another concern that was repeatedly stated by the participants involved the reliability of diagnostic reports received from accredited and authorized diagnostic centers and clinics.

Schools have the right to appeal to the KHDA if there are serious areas of concern and parents refuse to send their children for assessment. The KHDA frequently grants schools the right to cease re-registration for these children, and parents are faced with the dilemma of either labeling their children with a SEND and continuing their education, or

refusing and keeping them at home. For most parents, education is non-negotiable and thereby, they are compelled to send their children for assessment. Unfortunately, some of the more affordable clinics and centers use outdated tools and diagnostic procedures that consequently result in unreliable reports.

Early diagnosis and intervention helps SEND children gain acceptance and more academic skills when placed in mainstream classroom environments. Total "inclusion is revered as the panacea for combining special needs kids with general populations into our regular classrooms" (Wright, 1999, p.11). Inclusion is not about any consistent rule but about what seems to be the fair things to do for students. And allowing all children, no matter what their socio-economic background is, to receive reliable assessments and intervention, is what seems fair for these students' future.

## 6.2 Recommendations

This survey highlights the importance of user feedback in planning and developing local diagnostic services. It demonstrates that parent support organizations can provide an extremely important source of support to families at, and after, the time of diagnosis. The majority of parents predicted and experienced a range of both positive and negative consequences for themselves and their children. The process of coming to terms with the diagnosis appears to involve accepting a child's often serious limitations while also keeping in mind that improvement can occur under the right circumstances (Mansell & Morris, 2004). SEND constitutes a range of conditions, within which there are widely differing levels of severity, and the process of receiving and adapting to the diagnosis is complex and diverse. Further research is needed to confirm these findings and to produce clearer, evidence-based interventions to help parents during this long and turbulent process of change.

The investigation of parental beliefs is a potentially productive endeavor as it reflects parental influences in the child's social, emotional and academic future. Super and Harkness referred to the "psychology of caretakers", while Serpell noted parental beliefs provides a medium whereby they influence child development (Danseco, 1997, p.42). "These familial factors are thus dynamic, non-static entities rather than "objective" social address variables impacting on child development" (p.42). Danseco (1997) implies that

investigating the interface of culture, parental beliefs, professional beliefs, and childhood disability is necessary to inform what constitutes effective intervention. "Examining these issues is imperative if research and programmatic efforts are to be relevant and responsive to the demands of parents, children, and the broader society" (p.50).

Therefore, it is imperative for the governmental entities in Dubai to respond to parents' concerns regarding the high costs of assessments and intervention as well as practice strict quality control with regards to report reliability. Locals have the option to assess their children in free governmental clinics and centers as well as receive therapies and interventions from the CDA. But, the actual setback concerns expat parents who are required to pay for all services including education, assessment, intervention and all kinds of support essential for the child at school and at home. As stated previously by a FS teacher, services and privileges should be offered to residents of Dubai, and especially to children who were born there (refer to Appendix 4.5).

## 6.3 Future Research

In the UAE, there is a vast difference in services provided to locals and expatriates. This difference was an oversight in this study, and therefore it is recommended for future research that different studies should be conducted in order to measure attitudes of local and expat parents of children with SEND towards diagnosis and intervention in Dubai. Also, it is of extreme importance to have the research administered in both Arabic and English languages in order to appeal to the vast majority.

Findler, Vilchinsky and Werner (2007) stress the importance of using multidimensional scales that differentiate between the three components of attitudes; affective, cognitive, and behavioural, and of examining the relationship between each of these components and a range of variables, including demographics, personality, and situational ones. In terms of methodology, the authors recommend updating and refining existing scales, reporting the psychometric properties of the scales employed, using indirect attitude measurement methods, and relating specifically to the attitude referent (p.167).

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# APPENDICES

## Appendix 1 – Email to school principal

**Appendix 2 – Email to parents**

Gmail ▾

COMPOSE

Inbox (27)
Starred
Important
**Sent Mail**
Drafts
[Gmail]Trash
Personal
Travel

Yomna ▾

Parent Survey    Inbox  x

11/29/16
Dear Ms Yomna, I am sorry for the delay in reverting We are happy to support ...

**Yomna El Hariry** <yomna.elhariry@gmail.com>    11/30/16
to

Dear Parents,

My name is Yomna El Hariry, a former teacher at Al Salam Private School. I am currently pursuing my degree in higher education in order to achieve a Masters in Inclusion and Special Education.

I have designed a survey for my dissertation titled "Attitudes of parents of young children with Special Educational Needs and Disabilities (SEND) towards diagnosis & intervention in Dubai and its implication on education", and would truly appreciate your time spent participating in it.

https://www.surveymonkey.com/r/8GZYBLJ

Please note that all information provided will be completely anonymous and confidential. No centers, schools or any names will be disclosed at any point in the research paper.

Your views and experiences are truly valuable.

Sincerely,
Yomna El Hariry

**Appendix 3.1 – Mansell & Morris questionnaire: Table 2**

*Table 2*  **Children receiving each diagnosis, and questionnaires returned**

| | Period of diagnosis | | | | | |
|---|---|---|---|---|---|---|
| | 1995–7 | | 1998–9 | | 1995–9[a] | |
| | Children (n = 46) | Returned (n = 27) | Children (n = 54) | Returned (n = 27) | Children (n = 100) | Returned (n = 55) |
| Autism | 23 | 15 | 21 | 8 | 43 | 23 |
| Asperger syndrome | 9 | 9 | 8 | 7 | 17 | 16 (+1) |
| ASD-NOS | 12 | 3 | 19 | 8 | 31 | 11 |
| Autism (mild) | 1 | 0 | 1 | 1 | 2 | 1 |
| Asperger (mild) | 1 | 0 | 1 | 1 | 2 | 1 |
| ASD-NOS (mild) | 0 | 0 | 3 | 1 | 3 | 1 |
| Not specified | – | 0 | – | 1 | – | 1 |
| *Other diagnoses* | (n = 10) | | (n = 3) | | (n = 13) | |
| Semantic pragmatic disorder | 2 | – | 0 | – | 2 | – |
| Probable/possible ASD | 1 | – | 2 | – | 3 | – |
| Language disorder only | 3 | – | 1 | – | 4 | – |
| Learning difficulties | 2 | – | 0 | – | 2 | – |
| No diagnosis | 2 | – | 0 | – | 2 | – |

ASD = any autistic spectrum disorder.
ASD-NOS = autistic spectrum disorder not otherwise specified; atypical autism; pervasive developmental disorder not otherwise specified.
[a] The (+1) refers to a returned questionnaire whose date of assessment could not be traced.

**Appendix 3.2 – Mansell & Morris questionnaire: Table 4**

*Table 4*   **Recommendations for the local diagnostic service and parents' support group (numbers indicate questionnaires including the recommendation)**

*Comments on the prognosis provided by the local diagnostic service*

| | |
|---|---|
| Counselling for parents should be available to deal with the diagnosis | (4) |
| Do not provide too bleak a prognosis | (2) |
| Provide more information about the long-term effects of autistic spectrum disorders | (2) |
| Reassure parents there are things they can do | (1) |

*General comments on information on support and treatment provided by the local diagnostic service*

| | |
|---|---|
| Provide more information on the support and treatment options available | (6) |
| Before the diagnosis, provide information about how to access help, support and treatment | (5) |
| During a follow-up session, provide information about further support and treatment programmes | (5) |
| Keep the parents informed of the likely diagnosis before the formal diagnosis is given | (4) |
| Provide a suggested reading list at the time of diagnosis | (3) |
| Provide a home visit early on to help with behaviour and provide hints | (1) |
| Provide a 'call-back' policy | (1) |
| Provide a regular organized treatment review system like at the Maudsley Hospital | (1) |

*Comments on specific sources of support and treatment*

| | |
|---|---|
| Provide more information regarding dietary intervention | (5) |
| Provide help and advice on how to deal with schools, what is available, and getting a place | (4) |
| Provide information on managing behaviour and potty training | (1) |
| Mention the NAS conferences | (1) |
| Provide information about secretin | (1) |
| Provide information on benefits (DLA) and on help from social services, especially for single parents | (1) |
| Provide information on respite care | (1) |
| Explain about the services at the Maudsley | (1) |

*Other recommendations for the local diagnostic service*

| | |
|---|---|
| Reduce the waiting list | (6) |
| Have a mobile diagnostic service | (1) |
| Provide access to a specialist on Asperger syndrome | (1) |

*Recommendations for local parents' support group*

| | |
|---|---|
| It would be good to have some workshops at weekends (especially Sundays) or school holidays | (2) |
| Provide accurate information about the results of different treatments and their suitability | (1) |
| Provide names of local people to call for information | (1) |
| Provide more courses on specific interventions, such as behavioural management | (1) |
| Provide more books on Asperger syndrome | (1) |
| Provide a list of local 'autism-friendly' places, e.g. barbers, shops, restaurants | (1) |
| Place leaflets, posters etc. about autistic spectrum disorders in nurseries to raise awareness | (1) |

**Appendix 3.3 – Mansell & Morris questionnaire: Table 5**

*Table 5* **Sources of information, usage by respondents, most common frequency of use, and mean ratings of usefulness (1 = not at all, 4 = extremely)**

| Source of information | % respondents | Frequency of use | Ratings of usefulness (1–4) |
|---|---|---|---|
| ✗Family services worker | 89 | annually | 3.5 |
| Speech and language therapist | 83 | annually | 2.9 |
| Educational psychologist | 77 | annually | 2.4 |
| Books | 69 | monthly | 3.3 |
| School teacher | 65 | weekly | 3.4 |
| Other information from local parents' support group | 58 | monthly | 3.5 |
| Consultant paediatrician | 58 | once ever | 2.6 |
| Internet | 54 | monthly | 3.2 |
| Newspapers/magazines | 53 | monthly | 3.1 |
| Clinical psychologist | 53 | once ever, annually | 2.7 |
| Local workshops/conferences | 52 | yearly | 3.4 |
| ✗Local open meetings of the NAS | 48 | monthly | 3.2 |
| Occupational therapist | 44 | annually | 2.8 |
| Family and friends | 41 | monthly | 3.2 |
| GP | 41 | annually | 2.3 |
| ✗Social worker | 33 | monthly | 3.0 |
| ✗Academic journals | 32 | monthly | 3.5 |
| ✗Early years course | 23 | once ever, annually | 3.4 |

**Appendix 3.4 – Mansell & Morris questionnaire: Table 6**

*Table 6* **Sources of support or treatment, usage by respondents, and mean ratings of usefulness (1 = not at all, 4 = extremely)**

| Source of support or treatment | % respondents | Ratings of usefulness (1–4) |
|---|---|---|
| Speech and language therapy | 87 | 2.9 |
| ✗Special unit or special school | 69 | 3.7 |
| Support at mainstream school | 42 | 3.1 |
| Occupational therapy | 39 | 2.9 |
| Change in diet | 35 | 3.2 |
| Behaviour management or parent training | 24 | 2.8 |
| ✗Early years course | 21 | 3.6 |
| TEACCH | 21 | 3.1 |
| Lovaas | 14 | 3.6 |
| Secretin | 10 | 1.8 |
| PECS | 8 | 2.8 |
| Options | 6 | 2.8 |
| Higashi | 2 | 4.0 |

Grouped as "Medication" (TEACCH through Higashi)

Other recommended sources of support and treatment: homeopathy (3); Professor Taylor at the Maudsley Hospital (2); cranial osteopathy (1); NAS helpline (1); Portage (1); AIA (1); SALT (1); Seroxat (1).

**Appendix 3.5 – Mansell & Morris questionnaire: Table 7**

*Table 7* **Ratings of useful and difficult features of the diagnosis (percentage of respondents endorsing 'agree' or 'strongly agree')**

| | |
|---|---|
| I was relieved that a diagnosis had been made | 90 |
| I have a better understanding of my child's behaviour | 87 |
| I have been able to accept my child's behaviour | 83 |
| We have been able to adapt family life to my child's behaviour | 74 |
| I have been able to get practical help for my child | 71 |
| Other people have a better understanding of my child's behaviour | 56 |
| It helped me stop blaming myself | 49 |
| I have been able to get support for myself | 44 |
| I have become more worried about my child's future | 73 |
| Other people do not understand the diagnosis | 68 |
| It is difficult to know which problem behaviours are caused by the disorder and which are not | 65 |
| I was shocked by the diagnosis | 41 |
| ✗My child has been treated worse by other people | 14 |
| Diagnosing my child has been financially exhausting | |

# Appendix 3.6 – Mansell & Morris questionnaire: Table 8

**Table 8**  How parents' attitudes to the diagnosis have changed over time (numbers indicate questionnaires describing an attitude)

*Reactions to the diagnosis*

| | |
|---|---|
| We were shocked/upset/devasted | (12) |
| The diagnosis confirmed our feelings | (6) |
| ✗We already knew that our child had an autistic spectrum disorder | (6) |
| The diagnosis helped explain our child's behaviour | (4) |
| We were angry about the diagnosis | (3) |
| ✗We got the false impression that the future would be very bleak for our child | (3) |
| ✗We did not face the truth about the diagnosis | (2) |
| We welcomed the diagnosis | (2) |
| It is difficult to seek support before getting the diagnosis | (1) |
| ✗We asked 'Why us?', 'Why him?' | (1) |
| ✗Our anxiety on answering questions may have affected the diagnosis | (1) |
| Waiting for the diagnosis was very stressful | (1) |
| ✗The diagnosis allowed us to lower our expectations | (1) |
| Fortunately, we had started seeking support before the diagnosis | (1) |

Getting my child diagnosed has been worth the financial burden

*Changes in attitudes and experience over time*

| | |
|---|---|
| Our attitudes to the diagnosis have not changed over time | (8) |
| Our child has made good progress | (8) |
| ✗Other people have little understanding of autistic spectrum disorders | (6) |
| ✗Once diagnosed I was left and my child was not seen by anyone | (4) |
| It takes several years to come to terms with the diagnosis | (4) |
| The label has allowed us access to useful resources | (3) |
| ✗It is difficult that children with autistic spectrum disorders look 'normal' | (2) |
| ✗We mourned our 'lost child' | (2) |
| The label allowed us to meet other families | (2) |
| ✗There were times when I felt responsible for my child's problems | (1) |
| ✗Other parents are less sympathetic to autistic children who are high functioning | (1) |
| A vague 'grey-area' diagnosis makes it very difficult to receive help | (1) |
| ✗We take each day at a time | (1) |
| ✗We have become thick-skinned to deal with other people's reactions | (1) |
| The increase in public awareness has helped | (1) |
| ✗I have treated my child like a 'normal' child | (1) |

*Present conclusions about the diagnosis and the future*

| | |
|---|---|
| We wish that our child had been diagnosed earlier | (7) |
| We have become more accepting of the diagnosis | (6) |
| The label has been a good thing | (5) |
| We are unsure whether the diagnosis is correct | (5) |
| We have become more aware of the lack of resources for our child | (4) |
| ✗We have adapted to our child's behaviour | (3) |
| We know there will be difficulties ahead | (2) |
| ✗We are lucky that our child does not have severe difficulties | (2) |
| We are still upset and concerned about the diagnosis | (2) |
| ✗My child's difficulties have affected my health | (2) |
| ✗We will have to explain the diagnosis to our child in the future | (2) |
| There is less help available for children ~~with ASD~~ as they get older | (1) |
| ✗The process has been an emotional yo-yo | (1) |
| ✗The label has been counterproductive | (1) |
| I feel isolated | (1) |
| ✗The autistic society is there for me | (1) |
| ✗My child and I face the difficulties together | (1) |
| ✗Autism is interesting and a challenge | (1) |
| Our child is a special and unique person | (1) |
| ✗I respect and admire parents of children with severe difficulties | (1) |
| We were lucky that our child was diagnosed early on | (1) |

**Appendix 4.1 – Interview notes with Mona**

Nursery Manager     (Mona)
Nov. 24, 2016
11 am  :  ≈ 25 minutes

Q. How do parents usually react when they are informed that their child may require medical assessments due to concerns from the nursery?

A. Complete Denial! They see that their kids are "normal" at home. Some parents are even doctors & they still deny our concerns. Around 80% of our parents react that way.

We tell them we can observe the difference. We have around 140 children enrolled in the nursery each year.

I guess if these children have older siblings, parents can compare their behaviour. Many parents have only 1 child, or a young baby, so they cannot tell what behaviour is expected at this age.

I had a parent once who had triplets, and she still couldn't see that one of them was developing differently

One couple decided to move their child to another nursery. As we would expect, the other nursery had similar concerns regarding their child.

I have another Parent, who is well-educated, and she noticed something different about her third child. She actually approached us and asked for the SENCO to observe her daughter. Her daughter was later diagnosed with ASD.

Some parents refuse to assess because of financial costs. Once, a grandparent came in with concerns regarding her grandkid, but after she found out they had to pay for a shadow teacher if the child was diagnosed with a condition, she refused.

Q. Are there enough options for parents to get their children assessed & diagnosed in Dubai?

A. Yes there are enough options, but very costly. Many parents self-educate themselves to try to cut down costs of therapies. Unfortunately, schools do not allow parents to become their children's shadow in &class. This is another financial burden parents must endure.

I noticed that the highest percentage of children diagnosed here with a SEN have engineers as parents. It's quite interesting!

Q. Your views regarding costs of diagnostic services.

A. V. expensive. Schools don't charge anything.

But we charge here in the nursery for the speech therapist to work with children with speech delay, even if the children are not diagnosed.

Q. Do you believe intervention / therapies are effective in producing required results?

A. Early intervention is very effective for the child. We have witnessed how late intervention affects a child's future. Our colleague here enrolled her child in the nursery when he was 2 years old. We all noticed his odd behaviour, but she refused to accept our observations & did not take him for assessment. Later, when she travelled to Ireland, her son was diagnosed with ASD at the age of 5. She regretted not having diagnosed him earlier & was very upset at the lost opportunity of having him diagnosed earlier & starting intervention.

Most of the children diagnosed with SEN are very intelligent academically. Their differences are in their social and behaviour traits.

We usually have 10 cases of SEN each year out of 140 new enrollments.

**Appendix 4.2 – Interview notes with Amy**

Team leader & Nursery teacher (Amy)
Dec. 4, 2016
1:30 pm : ≈ 15 minutes

Most parents are in denial. I have to prove to them my concerns. First I speak to parents, tell them that their child has difficulty coping in class. Then I involve the counsellor or even the manager if they still don't accept my concerns.

One parent fainted, even though he was her 5th child she didn't notice that he was different. She was in complete shock. Other parents ask to give their kids time to cope, and sometimes we show parents videos of concerned behaviours, even though we know its not allowed. But we need to convince them.

There are options for parents but they are unreasonable. These centers are too expensive and after their child is diagnosed, they still have to pay for a shadow teacher in the nursery and school. These parents are all middle-classed families, how can they afford all these expenses?

I don't know if reports are reliable, I haven't seen any!

Early intervention is a must - absolutely! At this age, they form their habits and personalities.

E's son is an example. She didn't accept that her son was different till he turned 5. It was too late then, and she really regretted it.

Parents must find the appropriate place to have their child assessed. They have to make sure that their child's teacher is suitable for his condition. And intervention must begin at the right time.

## Appendix 4.3 – Interview notes with Noor

Nursery Teacher        (Noor)
Dec. 4, 2016
10 am ;  ≈  10 mins

1. Parents are very cooperative. Sometimes they are initially in denial, but it's not a big issue. They get over it quickly & want to know what they can do to help their child. I never mention any of these concerns to the parent alone. I always have the counsellor with me to inform the parents.

2. It depends really. This year one parent was really responsive.
The previous years some parents would take their kids out of the nursery & put them somewhere else.
Only a few years ago, Parents didn't have the option to take their children for assessment. Everyone had to deal with the child and manage.

3. Yes now there are. Even at school there are more people involved for children with special needs. The SENCO & M. are always here to help out.

4. The costs are average, around 7,000 AED for a complete psycho analysis excluding speech assessment. Sometimes, for certain parents, the cost can affect their decision to get their child assessed.

5. Yes, the reports are reliable.

6. Yes, they are.

7. I don't know, I suppose they do.

8. (skipped)

9. They have to send their children to therapies. I do what is recommended by the center. They should look at their child's improvement & continue. They should also research how they can help at home and be up-to-date.

**Appendix 4.4 – Interview notes with Priya**

(Priya) FS2 Class teacher
Dec. 4, 2016
11 am : ≈ 10 mins

1. Mixed feelings of reluctance, fear and anxiety is seen in parents when they are informed that their young child may require assessment due to concerns from the school.

2. I feel they are scared and reluctant to accept that there might be something wrong.

3. Yes, I guess there are enough options.

4. I feel it's expensive. If it was just a matter of one time it's still alright but I guess these assessment procedures are repeated every 2 years which is taxing for parents mentally as well as financially.

5. I am sure they are.

6. I strongly agree to this as these therapies yield benefits in academic achievements and behaviour of the child.

7. It helps to include the child in the main stream by providing them with the help they need (emotional, academic, etc.)

8. (Skipped)

9. Accept their children as they are, support them by enhancing caregiving environment which is conductive to their growth.

**Appendix 4.5 – Interview notes with Rosalinda**

FS2 class teacher    (Rose)
Dec. 5, 2016
10:40 am   : ≈ 15 mins

1. They feel worried and shocked. Some live in denial as no parent would wish for their child to be different.

2. They feel their child would be neglected or looked down upon if their child ~~doesn't~~ gets assessed.

3. No, there are not enough centers for, assessing children. And the ones that are available are really far from maintown.

4. They are pretty expensive. The common man is not considered. Children who are from poor or low scale families are left to suffer because there are no measures put in place for them and their families.

5. Sometimes the reports are reliable, but you might still need to get a second opinion.

6. Yes, interventions and therapies are effective when followed up.

7. Early intervention is the best thing that can happen to a child with SEND.
   - It will help the parents have a more

Strategized way of catering for the child's developmental needs (academically, socially and medically).

- The child will benefit from sessions as the therapist will have planned measures which focus on the areas of concern.

8. I have a family friend who's child suffers from speech and language delay.
He was refused admission in many schools and the only school that agreed to take him was really expensive, and that was the cheapest after much survey.

When she couldn't cope with the burden of paying high fees, she had to send him back home while herself and her children remain here. This is really sad. At least children who are born here should have some sort of medical and academic benefits or privileges.

9. Don't live in denial. Get more medical opinions and when fully sure of the condition, work in partnership with those involved in the growth of the child.

Above all, make sure the child is not treated any differently from mainstream children. The child should not in any way feel less of a child or inferior.

**Appendix 4.6 – Interview notes with Ameera**

FS Learning Support- ~~poooog~~ (Ameera)
11 am    :   ≈ 10 mins
Dec. 5, 2016

1. Parents at the first stage are in denial, there
   is a blame game, the school is also targeted
   and finally when they understand in the 3rd
   or 4th meeting that its for their child's betterment,
   they agree for an assessment.

2. Parents many time feel that the school treats
   their children differently or that the school is
   targeting their child. Very few parents understand
   that the assessment could help their child further on.

3. Yes, through experience I've understood there are
   alot of centers but very few give genuine reports.

4. The assessments and the follow-ups are very
   expensive as a result many parents choose
   not to go ahead with the same as they
   cannot bear the costs.

5. As stated before, very few centers give a
   descriptive & genuine report.

6. Yes, interventions give you a clear picture of
   the child's needs, abilities and the areas where he
   is lacking. Thus intervention could give an
   insight into the child's needs & challenges.

7. As development takes place at a very young age, early intervention helps understanding the delays of these learning developments which otherwise would have hindered the child's further development.

8. We work closely with an intervention center. When we refer a child to their center we always get descriptive assessments and next steps and recommendations as what the school & home can do to help the child further. It also gives me great pleasure to express at this point that the KHDA has been very supportive of inclusive learning and school for all.

9. Parents are the key people to a child's learning. They are the primary source of overcoming any learning difficulty or challenge the child might face. To help a child empower these challenges he or she needs constant support from parents to bring out the best and help him or her live and grow in society peacefully.

## Appendix 4.7 – Interview notes with Katie

Therapist at a Dubai-based Intervention Center
Telephonic interview       (Katie)
Dec. 10, 12 pm  :  ≈  10 mins
    2016

1. I noticed that their first reaction is being anxious and having the fear of the unknown because they don't know what will be the result of the assessment, or why they even have to go for the assessment.

2. Some parents are open minded enough to accept their child will need to have an assessment, but there were instances that some parents wouldn't agree to bring their child and would even question why they have to do the assessment.

3. I believe there are enough centers that would give better options for parents to cater for the needs of their child.

4. Honestly, I believe it is indeed expensive.

6. I definitely believe doing therapies and interventions would help these wonderful children. I for example am a therapist and I have personally witnessed the improvements on the child when he started having therapies.

5. In my opinion, I believe the results are reliable since the physicians or psychologists doing the assessment are the expert in their own field,

they have studied for so many years and gained a lot of experience. They are all professionals.

7. I strongly suggest an early intervention be done to children who require therapies. The earlier the intervention done to them the more positive outcome will be expected. The child will have many possibilities for his future once an early intervention was made.

8. (skipped)

9. I know from my observation that being a parent and having a child with special needs is really a challenging situation. If given the chance to give them suggestions, I will advice them to seek professional help as soon as possible. As a therapist, I can say the sooner the intervention done to the child, the more easier their life will be. I have experienced before that the child was already 11 years old when he started to have therapy and it is really hard for us on the professional side. I can only imagine what more if the child is at home? If only he could have been given early interventions he could have done some developmental milestones as per his age already.

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**Appendix 4.8 – Group interview notes: Jane & Deepti**

School counsellor & Head of SEN    (Jane)
Nursery & FS SENCO           (Deepti)
Nov. 23, 2016
12:30 pm :  ≈ 30 mins


1.  Defensive, angry

It varies really, with severe cases the parents understand and their attitudes are more positive because it shows. But in certain cases of early intervention, the signs are not too obvious.

With first borns, ~~and~~ new parents have nothing to compare their child's behaviour to. It's easier if there are siblings. It really depends on the parents' sensitivity, education, and exposure and family history.

There has to be a planned strategy to inform parents. It's not fair to bring it up all at once. We take it step by step and then finally ask for an assessment.

Considering the expenses as well, parents should really try to do their HW and work with the child. Sometimes it takes us 9 to 12 months to prepare parents & tell them that their child might need an assessment.

2. Centers are really making parents hesitate. Many of the reports are very unreliable, we got 3 inconsistent diagnoses for the same child from the same center. And it was a very reputable clinic. When we called them to clarify, they said that these parents are our clients, and they are entitled to get whatever they ask for.

Another student, we asked his parents for academic and behavioural referral. So the parents chose a psychiatrist recommended by the KHDA. We recieved an atrocious report where they used outdated diagnostic tools, He was a clinical psychologist

Many of these reports are inconsistent, and it's very disappointing. They deprive the child of his right to get proper intervention.

So we really can't blame parents if they are hesitant to get their child assessed, after they hear of such cases especially.

3. We get skimpy reports from affordable centers unfortunately. The school recommends to parents certain reliable centers, but not all parents can afford them.

4 + 5 discussed earlier.

6. Intervention definitely helps, especially that many children can be wooed off the help later on.

7. We usually have 2 different outcomes. It's either that or parents are washed out after the diagnosis and so rely on the school support solely. This isn't always enough for the child's requirements.

8. Discussed earlier.

9. We view tremendous change with regards to kids diagnosed with ASD and have undergone intervention.

Parents can gradually reduce the number of hours of therapies, and focus on the areas that the child truly requires.

Also, parents must make sure that the child's teacher is capable and qualified enough to support their child in the mainstream classroom.

**Appendix 4.9 – Group interview notes: Sally & Golnar**

Nursery & FS SENCO            (Sally)
Learning Support             (Golnar)
Dec. 11, 2016
1 pm : ≈ 15 mins

1/2 Denial! It takes a long time to convince
the parents that there is an issue.

Assessment is the second step, and it usually
takes us months to convince the parents.

There are also financial constraints because
the price of assessments and diagnosing is
very high. We do have a list of small
centers as well, but still there is the cost
of therapies and follow-ups.

If the child has severe needs, they require
a shadow teacher and many parents
can't afford that too.

There is also a lot of ignorance, some parents
think it's a phase and their child will
grow out of it. They tell us the same was
with their older brother or sister and now
they are settled.

8. No there are not enough options,
because the centers do not cater to parents
with different needs. Some institutes
provide free assessments for locals, but

the packages for expatriates range from 10 to 15 thousand a month, which is inhuman.

Also, many parents complain that there are waiting lists in the center that will assess their child, and some even wait for 2 months before the diagnosis.

4. very expensive.

5. Yes, we recommend the centers that provide reliable results.

Some reports are not very reliable to be honest, the battery of tests the use is very outdated and so we know the quality we receive from the Clinic is not very good. We definitely don't recommend these centers or clinics.

6. Yes, we notice an overall improvement. Most of our students benefit mostly from ABA and Speech therapy. We have a lot of high-functioning autistic students and we can see the gradual process with the support of intervention & therapies

7. Intervention is more effective at a younger age, therefore early intervention is very important.

8. We have many students who had speech delay and now they are at par with the rest of the class thanks to intervention. One of our students is now gifted in reading thanks to the efforts of parents and constant therapy.

9. Acceptance is the first step, ~~sssss~~ We knew there's a lot of stigma around it. But they can work towards it and after a few years they will notice how effective the therapies have been.

It's very difficult for older kids to fit into an academic setting if they haven't been diagnosed & intervened early on.

There is no vocational setting in Dubai sadly. Once students with SEN graduate from high school, there isn't much for them to do.