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Children with Autism Spectrum Disorder in the Context of Arab Countries and Cultures.

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Declarations

This thesis has not been submitted for an award or degree at any university or institution. Where material has been derived from other sources, full bibliographical information has been provided.

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Summary

The field of Autism Spectrum Disorder (ASD) in the Arab world is new. The dearth of ASD research in the Arab world is well recognised. There were no data available in the field of ASD in the Arab context collectively. Therefore, ASD researchers should attempt to discover the state of ASD from the Arab perspective. This thesis has attempted to expand our knowledge of the field of ASD in the Arab context, in particular children with ASD and their families. In Chapter 1 an introduction on Arab countries was presented including geography, religion, language, culture, and information about typical family systems. Further, the current state of ASD in Arab countries and cultures was discussed in terms of its diagnosis, prevalence, services available for individuals with ASD, and Arab parents' stress and needs profiles. Four empirical studies then followed (Chapters 2, 3, 4, 5). In the first study (Chapter 2) a systematic scoping review of social, educational, and psychological research on individuals with ASD and their family members in Arab countries and cultures was undertaken, highlighting many unexplored areas for research. Chapter 3 then presented an investigation of support needs of Arab families of children with ASD living in the United Kingdom (UK). Chapter 4 explored experiences of special educators from a special school on using a structured numeracy intervention with their pupils with ASD. The final study (Chapter 5) then carried out an initial evaluation of a structured numeracy intervention with children with ASD in Arab families living in the UK by training and supporting their parents to deliver the intervention at home. In Chapter 6 the findings from the four empirical studies were discussed, along with their implications for practice and future research. Overall this thesis has contributed new knowledge in relation to the field of ASD in the Arab context.

Chapter 1: An Introduction to Autism Spectrum Disorder in the Context of Arab Countries and Cultures

The focus of this thesis is children with Autism Spectrum Disorder in the context of Arab countries and cultures. In this introduction, I will first describe Autism Spectrum Disorder. Further, to enhance the non-Arab reader's understating of this thesis, it is necessary to present a brief orientation to Arab countries including geography, religion, language, culture, and information about typical family systems. In addition, Autism Spectrum Disorder in Arab countries and cultures will be described in terms of its diagnosis, prevalence, services available for individuals with Autism Spectrum Disorder, and Arab parents' stress and needs profiles.

An Introduction to Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder defined by impairments in social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities. Social communication and social interaction domains consist of three criteria that must be endorsed for an ASD diagnosis: impairments in social- emotional reciprocity, misinterpreting non-verbal interaction, and difficulty in making, maintaining and understanding relationships. The restricted, repetitive behaviour domain involves four general aspects of sensory-motor and cognitive examples of repetition and restriction, two of which must be endorsed for an ASD diagnosis: abnormal focus on inappropriate items, addicted to routines, repetitive movements or speech, and hyper- or hypo- reactivity to sensory stimulation (American Psychiatric Association, 2013). Under the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria, individuals with ASD must show characteristics from early childhood, even if those characteristics are not recognised until later. The diagnostic criteria for ASD have been updated in the DSM-5 to incorporate four disorders from the DSM-4: autistic disorder, pervasive developmental disorder not otherwise specified, and Asperger Syndrome. DSM-5 also differentiates the level of support an individual may need: Level 1 requiring support, Level 2 requiring substantial support, and Level 3 requiring very substantial support (American Psychiatric Association, 2013).

The prevalence of ASD worldwide is estimated to be 1%, and is four times more likely to affect males than females (American Psychiatric Association, 2013). Recent data suggests an ASD prevalence in the United States of 1 in 59 children (Centre for Disease Control and Prevention, 2018), and 600,000 people (equivalent to a population prevalence of approximately 1%) in the United Kingdom (Buescher, Cidav, Knapp & Mandell, 2014).

An Introduction to Arab Countries and Cultures

The Arab world comprises of 22 countries spread from the Atlantic Ocean to the Persian-Arabian Gulf (Economic and Social Commission for Western Asia, 2013), with an estimated population of 414.5 million (The World Bank, 2017). These 22 countries, as defined by membership in the League of Arab States, comprise Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates (UAE), and Yemen (Harb, 2015). Arab countries are categorised as developing countries (International Monetary Fund, 2018). Developing countries are identified as countries that are less industrialised and have a low Human Development Index (HDI). The HDI consists of three main dimensions of human development: life expectancy at birth (the ability to lead a long and healthy life), education outcomes (the ability to obtain knowledge, measured by mean years of schooling and expected years of schooling), and national income (the ability to attain an appropriate standard of living, measured by gross national income per capita) (Human Development Indices and Indicators, 2018). The World Bank (2018) classified countries into four groups: low income, lower middle income, upper middle income, and high-income countries, based on gross national income per capita. Based on this classification, Saudi Arabia, Bahrain, Kuwait, Qatar, Oman, and the UAE have been classified as high-income countries, while the rest of the Arab countries are lower and upper- middle income countries.

Arab people are mainly tribes who live in the Middle East and North Africa (Yahiaoui & Al Ariss, 2017) including the Fertile Crescent (a crescent-shaped area covering the Arabian desert/Arabian Peninsula), the Gulf States (located in the Arabian Peninsula), the Nile Valley (located in eastern North Africa and the horn of Africa with Djibouti, Somalia, and the Comoros), and the Maghreb (located in western North Africa) (Yahiaoui & Al Ariss, 2017). The Fertile Crescent consists of Palestine, Jordan, Syria, Lebanon, and Iraq. People living in this area are particularly varied in ethnicities and religious denominations. This region has suffered decades of conflict and wars, especially the Israeli–Arab conflict and the United States invasion of Iraq in 2003 (Harb, 2015). The Gulf States includes the Kingdoms of Saudi Arabia, Bahrain, Kuwait, Qatar, Oman, and the UAE (Harb, 2015). Saudi Arabia has long been the holy area for all Muslims as it has Makkah and Medina, the two Muslim holy cities (Khusaifan, 2005). There are few political freedoms allowed by the monarchies of the Gulf States, as they rely on powerful family systems (Harb, 2015). The Nile Valley comprises Egypt and Sudan. Egypt is the most heavily populated nation among the Arab countries. Egypt is differentiated by its rich history, which includes an Ancient Egyptian Pharaonic past in addition to Arab-Islamic identity. It also plays an important role in inter-Arab politics and relations (Harb, 2015). The Maghreb consists of Morocco, Algeria, Libya, Tunisia, and Mauritania. This region has trade with Mediterranean countries, particularly France which is a previous colonial power; thus the French language is commonly used by some of the Maghreb nations including Morocco, Tunisia, and Algeria (Harb, 2015; Yahiaoui & Al Ariss, 2017). In general, the Arab population is defined as young in age and dependent on their family (Barakat, 1993; Mirkin, 2013). According to United Nations estimates, the Arab region has a median population age of only 22 years, compared to a world average of 28.5 years (United Nations, 2017).

The Arab world is diverse despite common culture, language, religion, and physical and geographic environment (Hadidi & Al Khateeb, 2015). The majority of people in these countries are Arab and Muslim. However, approximately 13 million people identify themselves as Christians, and constitute considerable portions of nationals in some Arab countries, e.g., 38.3% in Lebanon, 14.5% in Bahrain and 14.3% in Kuwait (Skirbekk, Stonawski, & Goujon, 2011). In addition, there are groups of people who follow the Druze, Jewish, and Hindu beliefs. There are also some key sub-populations of ethnic minorities. Twenty million people (40% of Moroccans and 20–25% of Algerians) identify themselves as belonging to the Berber-Amazigh ethnic minority (International Crisis Group, 2003), and more than five million people who live in Syria and Iraq identify themselves as Kurds (Aziz, 2011). In terms of language, formal and semi-formal Arabic are shared across the Arab region and dominate written communication. In addition, colloquial Arabic and dialects dominate verbal communication. The French and English languages are commonly used in nations where a powerful colonial past existed (Harb, 2015).

One of the most essential aspects in Arab communities is the culture. The Arab world has its own dominant culture that is established from what is most common and prevalent among Arabs (Barakat, 1993). Culture is represented by settings of living such as rural, urban, or Bedouin; by social patterns, e.g., mercantilist or agricultural; by social class such as high, bourgeois, and mass cultures; by religious and sectarian affiliations including Sunni, Shi'ite, Druze, Alawi, Isma'ili, Copt, Orthodox, Maronite, Catholic, Protestant, or Jewish; and by ethnicity, for example Kurd or Berber (Barakat, 1993). Certain cultural dimensions are particularly featured in the Arab culture, including high levels of religiosity across people, morality, honour, hospitality, and generosity (Harb, 2015). These shared aspects are socialised and continually strengthened through the family, the significance of which cannot be underestimated in Arab communities (Dwairy, Achoui, Abouserie, & Farah, 2006). Therefore, the Arab family is described below in terms of its structure, size, and marriage system.

The Arab Family Systems

The family has always been considered the centre of life in Arab communities. It is a substantial social security system for the elderly, sick, or disabled and it also provides economic support for children and youth, the unemployed, and other dependents (Rashad, Osman, & Roudi-Fahimi, 2005). The family is at the centre of social systems in all three Arab settings of living (Bedouin, rural, and urban) (Arab Human Development Report, 2002) and especially among tribes, peasants, and the urban poor. The family is the dominant social organisation through which individuals and groups obtain their religious, social class, and cultural affiliations. In addition, during times of individual and societal stress, the family provides protection and help (Barakat, 1993). In the traditional Arab family, the father has the authority and the responsibility (Mourad, Abdella Carolan, 2010). However, although cultural rules appoint family power to the father, it is the wife who actually practices power over the children. She is assigned to care for and to discipline them. Thus, sons and daughters are much closer to their mother than to their father. However, recent changes in family structure led to the democratisation of relationships between husband and wife, and father and children. Fathers are tending to relinquish their control over family life and to share power and responsibility with other family members. These changes have happened as a result of the appearance of competing socioeconomic units, the employment of women, and the movement of children to the city looking for education and work (Barakat, 1993).

Family structure.

The Arab region adopts the extended family form, with relationships based on affiliation to the father, who has great importance in the structure of Arab communities, particularly those whose roots extend to the Bedouin tribes. Extended families involve several generations, consisting of the married couple, unmarried children, married male children and their wives and children, unmarried paternal aunts and uncles, and grandparents (Al-Ghanim, 2012; Barakat, 1993; Hammad, Kysia, Rabah, Hassoun, & Connelly, 1999). The structure of the extended family provides many benefits including stability, consistency, and physical and psychological support (Dhami & Sheikh, 2000). In addition, the model of the extended family is recognised to be an important part of the community’s safety network (Al-Ghanim, 2012). Recently, families in most Arab countries have moved towards the nuclearisation of the family structure. The nuclear family consists of the father, mother, and children (Hammad et al., 1999). This movement has occurred in response to rapid urbanisation, industrialisation, higher employment, higher levels of education, exposure to the developed world, and the appearance of the middle class (Barakat, 1993). Despite an increasing trend towards nuclearisation in family structure, the family still displays a great deal of unity and integration among its members (Al-Ghanim, 2012). Relatives mostly keep closely interlinked in a web of good relationships that leaves restricted space for independence and privacy (Barakat, 1993).

Family size.

Family size in developing countries, including Arab countries, is generally larger than in developed countries (United Nations, 2017). Traditional Arab families desire to have more children. Having a son in the family means a great deal. The birth of a boy leads to more delight than the birth of girls. Having a boy could assist the family's safety and maintenance (Schvaneveldt, Kerpelman, & Schvaneveldt, 2005). The mean ideal number of children per family is perceived by Jordanian women to be 4.2. This number is slightly higher among women in rural areas than in urban areas (4.4 compared with 4.1). The ideal number of children declines as women's education increases; women with no education desire to have 4.9 children compared with only 4.2 children among those with higher education (Department of Statistics, 2010). Al-Garni (2000) documented that the idea of having a larger number of children in Arab families, particularly in Saudi Arabia, has its roots in the religion of Islam. There are three reasons for this. First, Islamic beliefs strongly advise individuals to have many children. The father believes that children represent a display of his manhood and self-identity. Second, polygamy (marrying more than one wife, up to four) is allowed for Muslims. Third, larger families are seen as a source of power and physical assistance in tribes, which permeate the Saudi society as it is made up of a collection of tribes. However, estimates show a rapid decline in fertility in the Arab region in the recent years. Total fertility varies considerably, from 2.1 per woman in Lebanon, Morocco, and Tunisia to over five children in Iraq and Kuwait. Recent estimates from Palestine and Yemen demonstrate a decline in fertility to around four children per woman (United Nations, 2017).

The marriage system.

In Arab culture, marriage is a distinct turning point that provides prestige, acknowledgement, and societal approval to both partners, especially the bride. Marriage in Arab communities presents a social and economic agreement between two families. In addition, it is a rite of passage into a socially, culturally, and legally approved sexual relationship (Rashad et al., 2005). The practice of consanguinity (marriage between relatives, especially between cousins) is a special aspect among Arab families (Islam, Ababneh, & Khan, 2018). Many Arab countries demonstrate some of the highest rates of consanguineous marriage in the world, ranging between 20-50% of all marriages, and in particular first cousin marriages (with average rates of about 20-30%) (Tadmouri et al., 2009). High rates of consanguineous marriage have, for example, been documented in Egypt (Mokhtar & Abdel-Fattah, 2001), Qatar (Bener & Alali, 2006), Oman (Mazharul Islam, 2017), UAE (Al-Gazali et al., 1997) and Yemen (Jurdi & Saxena, 2003). In particular, Bener and Alali (2006) found that the rate of consanguineous marriage among 1,515 married Qatari females was 54%, with 35% marriage between first cousins. Consanguinity in the Arab culture is not only limited to Muslim societies, as Christian societies in Lebanon, Jordan, and Palestine have also practised consanguinity, but less so than Muslims (Khlat, 1988; Vardi-Saliternik, Friedlander & Cohen, 2002).

In the Islamic religious context there is no incentive for consanguineous marriage (Akrami & Osati, 2007). Sociocultural determinants, such as keeping family structure and possessions, ease of marital plans, better relations with in-laws, and financial benefits relating to dowry appear to have a powerful effect on the preference for consanguinity in Arab culture (Bittles, 2008). In addition, Tadmouri et al (2009) reported that consanguineous marriage among Arabs is respected because it is believed that it boosts family coherence, simplifies financial prenuptial arrangements, provides a better compatibility between the spouses and other family members, offers lesser risk of hidden financial and health problems, and preserves the family land and property (Tadmouri et al., 2009).

It is documented that consanguinity has a negative impact on human reproduction and the health of offspring. The risk of birth defects, intellectual disability and neonatal and childhood death were found to be higher in children born to consanguineous mothers (Christianson, Howson, & Modell, 2006; Tadmouri et al., 2009; Mazharul Islam, 2017; Mokhtar & Abdel-Fattah, 2001). For example, the prevalence of Fragile X syndrome was found to be high among children of parents with consanguineous marriage (Al-Husain, Salih, Zaki, Al Othman, & Al Nasser, 2000).

There is a decline in frequency of consanguineous marriage (Assaf & Bradley, 2014; Hamamy, Jamhawi, Al-Darawsheh, Ajlouni, 2005). According to Tadmouri et al (2009) various factors may be playing a role in decreasing the consanguinity rates in Arab countries, including increasing female higher education levels, declining fertility which leads to lower numbers of appropriate relatives to marry, more mobility from rural to urban areas, and increasing economic status of families. For example, Islam et al. (2018) reported that there was a declining frequency in consanguinity in Jordan, with the rate going down from 57% in 1990 to 35% in 2012. Jordanian women with increasing age at marriage, higher level of education and living in urban areas, were less likely to enter into a consanguineous marriage.

ASD in Arab Countries and Cultures

Research on ASD has been largely conducted in Western countries which have considerable professional support services (Sharpe & Baker, 2011). There is limited research on ASD in non-Western, developing countries, including Arab countries where services for individuals with any type of special needs are less developed (Taha & Hussein, 2014). Research about ASD in the Arab world is a developing field (Hussein & Taha, 2013). It was not a subject of interest in the Arab world until the late 1990s (Hussein, Taha, & Almanasef, 2011; Hussein & Taha, 2013). Therefore, only a small body of research has been conducted on ASD in the Arab world (Al-Salehi & Ghaziuddin, 2009). The Arab world has only recently started conducting ASD research, compared with their Western counterparts (Alnemary, Alnemary, & Alamri, 2017). There were no data available for the condition of ASD in the Arab world collectively. In most cases, data are reported for each country separately (Taha & Hussein, 2014). ASD in Arab countries and cultures in terms of its diagnosis and prevalence, services available for individuals with ASD, and Arab parents' stress and needs status will be described.

Prevalence and diagnosis of ASD.

There has been an abundance of research on ASD prevalence, especially in the Western countries (Lenoir et al., 2009; Williams, Higgins, Brayne, 2006). However, in the Arab countries there is a scarcity of large prevalence studies (Taha & Hussein, 2014). The number of confirmed cases of ASD is unknown (Alnemary et al., 2017). The few small-scale studies conducted showed a wide variation in reported prevalence of ASD (Chaaya, Saab, Maalouf, & Boustany, 2016). For example, the prevalence of ASD was estimated to be 4.3 per 10,000 in Bahrain (Al-Ansari & Ahmed 2013) compared to

29 per 10,000 in the UAE (Eapen, Mabrouk, Zoubeidi, & Yunis, 2007) and 59 per 10, 000 in Saudi Arabia (Aljarallah, Alwaznah, Alnasari, & Alhazmi, 2007). On the other hand, the Sultanate of Oman had a lower prevalence of 1.4 per 10,000 in children less than 14 years old, based on data retrieved from all hospitals and social organisations that provide targeted services to ASD patients (Al-Farsi et al. 2011). Other studies examined frequency of ASD in clinical samples. For example, in Jordan from a clinical sample of children with global developmental delay (n= 229), 5.2% (n=12) had ASD (Masri, Hamamy, & Khreisat, 2011). In Libya, of a total of 38,508 children seen in a paediatric clinic in Tripoli, 128 children were diagnosed with ASD which gave an ASD prevalence of 1 in 332 children, approximately 3 per 1000 children (Zeglam & Maouna, 2012). These reported rates of ASD in the Arab countries are significantly lower than other studies in the Western countries (Al-Farsi et al. 2011; Zeglam & Maouna, 2012). Mostafa (2011) argued that the reported low prevalence of ASD might be due to under-diagnosis and under-reporting. There is a shortage of specialists to diagnose ASD properly and lack of parents' awareness to recognise symptoms and seek diagnostic clarification. In addition, cultural attitudes regarding disability might contribute to low reported prevalence of ASD due to the stigma associated with disability which make diagnosis of ASD cases difficult (Alshaban et al., 2017; Zeglam & Maouna, 2012). Ecker (2010) found that many families reject going to professionals and obtaining a diagnosis for their children due to the fear of discrimination and the stigmas associated with disability. In her work on mothers' perceptions of cultural stigma in relation to ASD in Saudi Arabia, Sulaimani (2018) found that some of the mothers were prevented by their husbands from taking their children to receive proper diagnosis. The tendency to refuse professional help derives from the stigma felt by fathers in a culture that misunderstands disability.

Published research on ASD diagnosis is scarce (Dababnah & Bulson, 2015). A literature review found few published studies on Arabic versions of ASD diagnosis tools (Eltyeb, 2017). For example, a study was conducted in nine Arabic speaking countries aiming to validate the Modified Checklist for Autism in Toddlers (M-CHAT) as an Arabic tool for the screening of ASD. The analysis included 228 children (122 of whom screened positive for ASD). Results indicated that the newly translated M-CHAT is an effective tool to use in the early screening of ASD in the Arab countries (Seif Eldin et al., 2008). However, Eltyeb (2017) recommended that Arab cultural, socioeconomical and geographical diversity should be taken into account when validating diagnosis tools. In addition, in a qualitative study that targeted 24 Palestinian parents of children with ASD in the West Bank, parents reported that none of the paediatricians or other primary care professionals used formal tools to screen for ASD and other developmental delays. Further, when developmental delays were recognised, none of the children obtained a comprehensive diagnostic assessment for ASD. Dissatisfaction with the diagnosis process was reported by half of the parents as it was long, expensive, and complicated (Dababnah & Bulson, 2015).

Services available for individuals with ASD.

Gulliford et al (2002) distinguished between the availability of services (having access) and the utilization of services (obtaining access). Obtaining access to services can be affected by personal aspects such as sociocultural, organisational difficulties, e.g., waitlists, and financial obstacles. Published research on service availability and utilisation for individuals with ASD and their families in the Arab world is scarce (Dababnah & Bulson, 2015). Health, educational, rehabilitation, and or social services for individuals with ASD and their families were lacking or of limited availability (Al

Jabery, Arabiat, Al Khamra, Betawi, & Abdel Jabbar, 2014; Al Khateeb, Kaczmarek, & Al Hadidi, 2019; Dababnah & Bulson, 2015; Dababnah & Parish, 2013; Dukmak, 2009).

For example, Dababnah and Bulson (2015) investigated access to ASD-related services among 24 parents of children with ASD in the West Bank. ASD-related services included screening, general therapies such as occupational therapy, or particular ASD interventions, e.g., applied behavioural analysis. Results revealed that parents reported limited or denied access to education, community-based services, and interventions. Some of the parents mentioned that their children did not receive any type of services, while some of the parents said that they had waited years to obtain therapeutic or health services for their children with ASD, due to waiting lists and centres unable to serve children with ASD. The parents faced extensive challenges to access services, particularly related to transportation, with transportation barriers including scarcity and cost. The parents stated the need for more specialised centres or schools with trained professionals that provide their children with a variety of services.

Dababnah (2018) also qualitatively examined the perspectives of disability service providers (n=7) at the West Bank agencies on access to ASD-related services. The providers stated that ASD-related services were limited and of poor quality. It should be noted that individuals with ASD and their families confront many social and cultural barriers that impact services utilisation (Dababnah & Bulson, 2015). Hussein et al. (2011) found that social stigma contributed to differences in parental awareness of developmental delays and then access to early intervention services. In Egypt, few families utilise ASD interventions or related services due to lack of awareness about ASD and effective interventions, insufficient community and financial resources.

Families of individuals with ASD who live in urban areas have more access to services, especially medical and health services, while individuals with ASD in rural areas stay at home with their family or extended family network (Mendoza, 2010). According to Taha and Hussein (2014) there are no current training colleges or institutions that provide vocational rehabilitation and employment support for adults with ASD across the Arab countries.

Special education schools and centres are the key sources for children with ASD in the Arab countries, which provide services including education that are mainly located in large cities (Alnemary, Aldhalaan, Simon-Cereijido, & Alnemary, 2017; Almassoud, 2010; Al- Zahrani, 2013; Hussein & Taha, 2013). In the Arab countries children with developmental disabilities including ASD do not receive educational services that meet their needs, or receive no education at all. However, inclusive education was proposed in some Arab countries (e.g., Jordan, UAE, Egypt, and Saudi Arabia) more than two decades ago as pilot projects consisting of a small number of schools. Most of the projects aimed to provide remedial and special education services in resource rooms in mainstream schools (Alkhateeb, Hadidi, & Alkhateeb, 2016). On the other hand, the majority of mainstream educational systems in the Arab countries are inadequately prepared to provide educational services to children with developmental disabilities. Barriers to inclusion included lack of teacher training and professional development, lack of parent involvement, lack of support services, and unclear inclusion policy regulations (Alkhateeb et al., 2016). Abu-Hamour and Muhaidat (2013) explored the attitudes of 92 Jordanian special education teachers towards the inclusion of pupils with ASD in public schools. 73 of the teachers stated that pupils with ASD should be included in public schools while 19 of the them were against the idea. In addition, for successful inclusion the teachers recommended prerequisite skills including independent skills, imitation skills, behavioural skills, playing skills, social skills, routine skills, attention skills, language skills, and pre-academic and academic skills.

Arab parents' stress and needs profile.

ASD is a lifelong impairment that impacts all racial and socioeconomic groups. ASD impacts the child's development; however, it can also considerably impact the child's parents (Cohrs, Leslie, 2017). Due to the wide range of difficulties and behavioural problems that these children encounter (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013), raising a child with ASD is commonly a challenging experience for parents. These challenges consist of receiving a diagnosis, identifying appropriate treatment and educational programmes, and paying for ASD services (Cohrs & Leslie, 2017; Ekas, Whitman, & Shivers, 2009; Whitman, 2004). As a result of managing these and many other challenges connected with raising a child with ASD (Ekas, Lickenbrock, & Whitman, 2010; Ekas et al., 2009), parents report greater mental health problems in themselves compared to parents of typically developing children (Ang & Loh, 2019; Benjak, Mavrinac, & Simetin, 2009; Khanna et al., 2011). It has been consistently reported that parents of children with ASD experience elevated levels of stress (Bonis, 2016; Costa, Steffgen, & Ferring, 2017; Hayes & Watson, 2013; Lai, Goh, Oei, & Sung, 2015) depression and anxiety (Hodge, Hoffman, & Sweeney, 2011; Jeans et al., 2013) compared to parents of typically developing children, and compared to parents of children with other disabilities, for example Down syndrome (Dabrowska & Pisula, 2010), Fragile X syndrome (Abbeduto et al., 2004), and intellectual disability (Totsika, Hastings, Emerson, Berridge, & Lancaster, 2011). Mothers of children with ASD are considerably more vulnerable to stress than fathers (Hastings & Brown, 2002;

McStay, Trembath, & Dissanayake, 2014). Koegel et al (1992) found a consistent stress profile in 50 mothers of children with ASD across multiple cultural and geographic locations and had children of different ages and functioning levels. This may be because mothers usually assume greater caregiving responsibilities of their children with ASD and more demanding domestic roles than fathers (Hastings et al., 2005; Jones, Totsika, Hastings, & Petalas, 2013; Pepperell, Paynter, & Gilmore, 2018).

Parenting stress is a discomforting psychological reaction to the demands associated with the role of being a parent (Deater-Deckard, 1998). Parenting stress is developed when there is a discrepancy between the perceived demands of parenting and the available resources, including personal and social, that should meet those needs (Abidin, 1995). There are several sources of parenting stress associated with the unique demands of caring for a child with ASD, including: an inconsistent profile of cognitive development, dependency needs that continue over the life span, poor communication skills, the demands of managing challenging behaviours, restrictions located in family opportunities, and financial duties for both present and future child-related expenditure (Bitsika & Sharpley, 2004; Moes, 1995). A number of studies have investigated child-related variables that are likely to predict heightened levels of stress of parents of children with ASD including the child's age (Cohrs & Leslie, 2017; Duarte, Bordin, Yazigi, & Mooney, 2005), and behaviour problems (Estes et al., 2009; Hastings & Brown, 2002; McConkey, Truesdale-Kennedy, Chang, Jarrah, Shukri, 2008; McStay et al., 2013; Lecavalier, Leone & Wilt, 2006; Lovell, Moss, & Wetherell, 2015) in particular, externalising behavioural problems (Zaidman-Zait et al., 2017), ASD symptom severity (Falk, Norris, & Quinn, 2014; Lyons, Leon, Phelps, & Dunleavy, 2010); as well as the child's adaptive behaviour (Hall & Graff, 2011; Tomanik, Harris & Hawkins, 2004). Parental factors have also been identified including the parent's age

(Duarte et al., 2005; Hastings & Brown, 2002), coping style (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Zaidman-Zait et al., 2017), and perceived self-efficacy (Hastings & Brown, 2002). The level of social support received by the parent has also been identified as a predictor of the stress experienced by parents of children with ASD (Bromley, Hare, Davison, & Emerson, 2004; Ekas et al., 2010; Zaidman-Zait et al., 2017).

Elevated parenting stress has been observed among parents of children with ASD in Western countries, but little is known about Arab parents of children with ASD. According to Dababnah and Parish (2013), published large-scale studies of parental stress and family burden of parents of children with ASD in the Arab world, particularly in the Middle East, are scarce. Raising a child with ASD is a profoundly challenging experience for parents in both Western and non-Western countries. However, ASD in non-Western countries such as Arab countries can be considerably more challenging (Al Khateeb et al., 2019). These challenges include lack of awareness about ASD, insufficient diagnostic procedures resulting in a delay in receiving a diagnosis of their children, the child’s dependency, discrimination and social stigma, lack of provided services including health, educational, and social, and financial burden (Al Jabery et al., 2014; Al Khateeb et al., 2019; Dababnah & Bulson, 2015; Dababnah & Parish, 2013; Zaki & Moawad, 2016). It has been noted that disability including ASD in the Arab culture is associated with social stigma (Dababnah & Bulson, 2015; Nazzal & AL-Rawajfah, 2018; Sulaimani, 2018; Crabtree, 2007). Sulaimani (2018) conducted a phenomenological study with mothers of children with ASD in Saudi Arabia to explore their perceptions and experiences of stigma associated with their children with ASD. Mothers reported that they suffer from blame, disrespect, pity, and shame. Mothers were blamed due to their children’s abnormal and improper behaviours that were attributed to lack of proper rearing. In addition, disrespect was directed at their children from friends or members of their families. Children were described as strange and mentally handicapped. Further, mothers were pitied by many individuals, who offered prayers requesting God to support the family with their difficulties. Dababnah and Parish (2013) found that some parents of children with ASD avoided social communication or discussing their child's condition outside of the family, as they did not want to be embarrassed.

As a result of these challenges that Arab parents of children with ASD encounter, a small body of research on the psychological impact of raising a child with ASD on Arab parents has been conducted (Al-Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016; Almansour et al., 2013; Dardas & Ahmad, 2015a; Dardas & Ahmad, 2015b; Dardas, 2014; Fido & Al Saad, 2013; O'leimat, Alhussami, & Rayan, 2019; Obeid & Daou, 2015; Rayan & Ahmad, 2017; Zaki et al., 2016). Researchers have found that Arab parents of children with ASD experience a high level of mental health problems including stress, depression, and anxiety in themselves compared to parents of typically developing children (Al-Farsi et al., 2016; Almansour et al., 2013; Fido & Al Saad, 2013) and compared to parents of children with other intellectual disabilities (Al-Farsi et al., 2016). It has been indicated that mothers of children with ASD are more liable to be subject to more mental health problems than fathers (Al-Farsi et al., 2016; Al-Khalaf, Dempsey & Dally, 2014; Fido & Al Saad, 2013). Among Arab parents, mental health problems including stress, depression, and anxiety were found to be associated with parent's age, gender, marital status, employment status, awareness about ASD, having more than one child with ASD, coping style, and level of social support received by the parent (Dardas & Ahmad, 2015a; Fido & Al Saad, 2013; O'leimat et al., 2019; Rayan & Ahmad, 2017; Zaki et al., 2016).

Researchers have recently started to explore the particular factors that may serve to directly decrease the negative psychological impact of raising a child with ASD (Ekas et al., 2009). Social support has been found to help in mitigating mental health problems in parents of children with ASD (Boyd, 2002; Bromley et al., 2004; Weiss, 2002). A great deal of research has found that social support assists in alleviating parenting stress, depression, and anxiety (e.g., Benson & Karlof, 2009; Boyd, 2002; Ekas et al., 2010; Goedeke, Shepherd, Landon, & Taylor, 2019; Mak & Kwok, 2010; White & Hastings, 2004; Zaidman-Zait et al., 2017). For example, mothers of children with ASD who received more informal support, especially from their spouses, reported lower levels of depression and parenting stress (Ekas et al., 2010).

Social support refers to the assistance an individual receives from other people. Support can be emotional, psychological, physical, informational, instrumental and material help that impacts the receiver's behaviour either directly or indirectly (Dunst, Trivette, & Hamby, 1994). Social support can be formal, such as that provided by an agency or organisation in the form of social, psychological, physical, or financial support, while, informal support can be provided by someone in the individual's network that consists of family, friends, neighbours and parents of other children with disabilities (Boyd, 2002; Bristol & Schopler, 1983). To initiate appropriate social support, professionals should begin with an assessment of the needs and wishes of the family (Albanese, Miguel & Koegel, 1996). Dunst, Trivette, and Jenkins (1988, p. 13) define need as "an individual's judgment of the discrepancy between actual states or conditions and what is normative, desired, or valued from a help seeker's and not a help giver's perspective". Comprehensive assessment of family needs can improve the formulation of meaningful interventions to address parents' particular concerns and desires (Baker, 1989; Plienis, Robbins, & Dunlap, 1988; Singer, Irvin, & Irvin, 1989).

Therefore, a considerable amount of research has been conducted on assessing family needs (e.g., Bailey & Simeonsson, 1988; Bailey et al., 1999; Derguy, Michel, M'bailara, Roux & Bouvard, 2015; Ellis et al, 2002; Siklos & Kerns, 2006; Hodgetts, Zwaigenbaum, & Nicholas, 2015; Huus, Olsson, Andersson, Granlund, & Augustine, 2017). For example, Hodgetts et al (2015) used the Family Needs Survey (FNS, Bailey & Simeonsson, 1990) to assess the needs of 143 families of children with ASD (2-18 years). Findings revealed that the most commonly unmet needs were the need for information about services for the child both now and in the future; family support and respite care. Further, child's age, mother's age and household income were significant predictors of more total needs. Having an older child or mother, lower income, and disruptive behaviours predicted more total unmet needs.

Research on needs of Arab family of children with ASD is absent. I could not find any studies that specifically assessed family needs across Arab countries. Families of children with ASD are "forgotten", as stated by one of the parents whom Dababnah and Bulson (2015) interviewed in their study on access to ASD-related services among 24 parents of children with ASD in the West Bank. Further, Al-Khalaf et al. (2014) mentioned that there are very few special education centres in Jordan that provide services to children with ASD. These centres do not have the resources and expertise that should help in meeting the needs of the families. Thus, Alnemary et al. (2017) in their systematic review of ASD research in the Arab world concluded that the considerable disparity of research outcomes across Arab countries increases concerns about the planning of, and investment in, meeting the needs of families of individuals with ASD in these countries.

The research included in this thesis is in part about Arab children with ASD and their families who live in the UK. Therefore, it would be important to highlight the concept of acculturation. Acculturation refers to changes that take place as a result of contact with culturally dissimilar people, groups, and social impacts (Gibson, 2001). According to Berry (2006) acculturation is most often studied in individuals living in countries or regions other than where they were born; that is, among immigrants, refugees, asylum seekers, and sojourners (e.g., international students, seasonal farm workers). The UK has one of the largest immigrant flows in recent history. It opened its borders to a diverse array of migrants, originating largely from Asia, Africa, the Caribbean, and the Middle East (Heath & Demireva, 2014). The dominant cultural practices and values in the UK are grounded in individualism. Whereas, collectivism (focus on the well-being of the family, clan, nation, or religion) informs the dominant cultural practices and values in the Arab world. As a result, there are differences in cultural values between Arab migrants and the UK society that is receiving them (Schwartz, Unger, Zamboanga, & Szapocznik, 2010).

It has been recognised that acquiring the beliefs, values, and practices of the receiving country does not automatically indicate that an immigrant will discard or stop endorsing the beliefs, values, and practices of his or her country of origin (Berry, 1980). Berry (1980) developed a model of acculturation in which receiving-culture acquisition and heritage-culture retention are cast as independent aspects. Within Berry's (1980) model, these two aspects intersect to establish four acculturation classifications including assimilation (adopts the receiving culture and discards the heritage culture), separation (rejects the receiving culture and retains the heritage culture), integration (adopts the receiving culture and retains the heritage culture), and marginalization (rejects both the heritage and receiving cultures).

To understand acculturation, the international context in which it occurs should be explored. This context involves the characteristics of the migrants themselves, the groups or countries from which they originate, their socioeconomic status and resources, the country and local community in which they settle, and their fluency in the language of the country of settlement. Schwartz et al (2010) indicated that there are two acculturation-relevant terms that should be considered: ethnicity and culture.

Ethnicity has become an integral aspect of the process of acculturation and migrant reception. Ethnicity is defined as membership in a group that holds a particular heritage and set of values, beliefs, and customs (Phinney, 1996). Culture refers to shared meanings, understandings, or referents held by a group of individuals (Shore, 2002). Rudmin (2003) argued that the similarity between the receiving culture and the migrant's heritage culture can assist to identify how much acculturation is required to adapt to the receiving culture. An additional factor that must be considered is language. A shared language is part of the fabric of national identity and migrants who speak other languages (or cannot speak the language of the country or region in which they are settling) may be considered a threat to national unity. Permutations among language, ethnicity, and cultural similarity impact the ease or difficulty associated with the acculturation process (Schwartz et al., 2010). Therefore, Arab migrants who move to the UK may require a degree of acculturation by adopting the practices, values, and identification of the UK.

Zane and Mak (2003) reported that beyond ethnicity, cultural similarity and language, other factors may also define which subgroups of migrants may encounter different types or degrees of acculturative challenges. For example, individuals who migrate as young children are more likely to obtain receiving-culture practices, values, and identifications easily and fluidly than those who migrate at older ages. Whereas individuals who migrate as adolescents or adults likely have vivid memories of life previous to migration, this may not be the situation for those who migrated as young children (Portes & Rumbaut, 2006). In addition, individuals who migrate as adults and especially those who arrive as older adults may experience the most difficulty or unwillingness in acquiring the practices, values, and identifications of the receiving community (Schwartz, et al., 2006).

The effects of acculturative process on health outcomes have received some empirical attention. Alegría et al. (2008) found that greater degrees of acculturation were associated with problematic health outcomes. In particular, assimilation (also referred to as the unidimensional approach) is associated with negative health outcomes. According to this unidimensional model, migrants acquire the values, practices, and beliefs of their new homelands and discard those from their cultural heritage (Alegría et al. 2008). Indeed, due to their reliance on a unidimensional approach (assimilation) to acculturation, Hispanics born in the United States, or who have spent a significant amount of time in the United States, are more likely to be diagnosed with psychiatric disorders than are Hispanics born abroad or who arrived more recently who practice the integration type of acculturation. (Alegría et al., 2008).

Some recent research has proposed that Berry’s integration category (also referred to as biculturalism) is often associated with the most positive psychosocial outcomes, in particular among young immigrants (David, Okazaki, & Saw, 2009). Bicultural individuals tend to be better adjusted reflected in higher self-esteem, lower depression, and prosocial behaviours (Chen, Benet-Martínez, & Bond, 2008; Schwartz, Zamboanga, & Jarvis, 2007; Szapocznik, Kurtines, & Fernandez, 1980) and are more able to integrate competing principles from the different cultures to which they are exposed (Tadmor, Tetlock, & Peng, 2009).

The acculturation process is of relevance to the research included in the current thesis. For the scoping review (Chapter 2) acculturation was reflected in decisions about the inclusion criteria. Specifically, studies were included if they focused on Arab populations living in non-Arab countries.

In the research reported in Chapter 3, the focus was on Arab families of children with ASD living in the UK. Although measures of acculturation were not included, acculturation was considered in relation to participation in the survey. The survey was anonymous with no name or other identifying information. This was partly due to the fact that in the Arab culture disability is associated with social stigma (Nazzal & AL-Rawajfah, 2018; Sulaimani, 2018) and so it was felt that families may be more likely to take part in an anonymous survey. In addition, Arab parents of children with ASD may be less willing to take part in a research project perhaps because a child's disability is too personal an issue for discussion with outsiders (Abu-Hamour & Al-Hmouz, 2014). Again, making the survey anonymous may have encouraged Arab families to take part in the research. In addition, during recruitment of families, acculturation issues were considered. For example, in presentations at meetings of parent groups the belief that a child with ASD is a gift from God was discussed. Arab parents of children with ASD may regard their children as a gift from Allah and feel blessed that God chose them to raise their special children (Nazzal & AL-Rawajfah, 2018; Dababnah & Parish, 2013). Furthermore, acculturation issues were considered in relation to the language of participants. Thus, during the recruitment process, to enable responses of Somali families, Somali language versions of the information sheet and consent forms were developed. In addition, Arabic versions of the survey, participant information sheet, and consent forms were provided to enable participation from Arab parents who had recently moved to the UK or had little of English.

The main focus of the study reported in Chapter 4 was not on an Arab population, and thus acculturation issues were not relevant. In the research reported in Chapter 5, the focus again was on Arab parents of children with ASD living in the UK. Values from the Arab culture were considered in this study. The focus was on recruiting mothers (so I was the same gender as the participants). In the Arab culture dealing with a person of the same gender could enable responding and communication in a comfortable and natural manner (Alotaibi, Dimitriadi, & Kemp, 2016). As with the study reported in Chapter 3, acculturation issues were considered in relation to the language of participants. Thus, an Arabic version of the numeracy intervention was provided to participants who had little English, the Arabic language was used during training and telephone support sessions, and all study information was again available in Arabic as well as English.

Structure of the Thesis

The remainder of this thesis is comprised of four empirical research studies and a general discussion chapter. Each of the empirical chapters has been, or will be, submitted for publication and thus is written as a standalone piece of work. The overall aim of this thesis is to explore the field of ASD in the Arab context, in particular children with ASD and their families. Accordingly, we first synthesize the current literature on social, educational, and psychological research on individuals with ASD and their family members in Arab countries and cultures (Chapter 2) in order to identify what is known and whether there are gaps in research evidence. Findings revealed that there were very few intervention studies, particularly academic interventions for children with ASD. It was also found that there were few studies exploring ASD services in terms of their organisation, effectiveness, or consumer perspectives. Indeed, there were no studies that particularly understand needs of families of children with ASD. Further, there were few studies of Arab families of children with ASD living outside of Arab countries such as UK. Therefore, this thesis has attempted to explore these neglected areas of research, including experiences of raising a child with ASD in the Arab context and academic intervention, in particular mathematics. Indeed, Chapter 3 focused on support needs of Arab families of children with ASD living in the UK. The chapter had two main aims: first to explore support needs, parental psychological distress, and parental relationships of Arab families of children with ASD. Second, to identify factors that predict these outcomes. An anonymous online/postal survey was provided in English and Arabic which included a demographic questionnaire and questionnaires measuring child behaviour problems, family needs, and parental psychological distress. Descriptive and regression analyses were used to address the research's aims.

To assist me exploring mathematics intervention for Arab children with ASD, the study reported in Chapter 4 was conducted. However, this study was conducted outside the Arab context. In addition to the core aim of the study, an additional aim was to build my own knowledge of a numeracy intervention to be used later in an Arab context. Chapter 4 was part of a research project that focused on an evaluation of a numeracy intervention implemented in a special school in 2017/2018 for pupils diagnosed with ASD, including some Arab pupils. This study was conducted in collaboration with Calthorpe Academy and another PhD student. Calthorpe Academy is a special school in Birmingham catering for around 380 pupils aged 2-19 years with severe intellectual disabilities. Pupils attending the school have diagnoses of Intellectual Disability, Autism Spectrum Disorder, Down Syndrome, or Profound and Multiple Learning (Intellectual) Disabilities; among others. The Autism Department provides education for around 80 pupils with diagnosis of ASD. The project's main aim was to evaluate the TEN-DD intervention (Teaching Early Numeracy to children with Developmental Disability) implemented in small group settings by the teachers and teaching assistants in Calthorpe Academy, and involved pre- and post-test measures to evaluate outcomes. Being part of this research project provided me with the opportunity to learn about the numeracy intervention, get involved in testing children's numeracy skills, and take part in training and supervising education staff in a special school. Thus, all the training that I obtained assisted me in conducting an initial numeracy study in the context of Arab families in the UK (Chapter 5). My role in this research project was to focus on the qualitative aspect of this intervention study. Therefore, the data in Chapter 4 focus on the experiences of special educators using the TEN-DD intervention with their pupils with ASD. Special educators were interviewed following an implementation of the TEN-DD intervention with their pupils with ASD to examine their experiences of using the intervention in their day-to-day work.

Chapter 5 focuses on an initial evaluation of the TEN-DD numeracy intervention with children with ASD by training and supporting their parents to deliver the intervention, over the course of an eight-week intervention period. Further, the study reported in this chapter aimed to contribute to the literature on teaching skills to children who come from an Arab background. The study incorporated pre-test and post-test assessments of the children's numeracy skills, but the main foci were feasibility questions about the intervention in this home context.

Chapter 6 provides a general discussion summarising the findings from the four empirical studies. Implications for practice, limitations, and future research are also discussed.

It is important to point out that this thesis contains two parts. The first part (Chapters 2 and 3) shows the lack of evidence, especially in education interventions, and the need for support as reported by Arab families raising a child with autism. The second part of the thesis (Chapter 4 and 5) was designed to provide me with experience in an educational intervention (a numeracy intervention) that might be used with children with autism and to start to build research evidence that would assist future work in Jordan after I finish my PhD studies. The research described in Chapter 4 was part of a wider evaluation of the numeracy intervention in a special school. Taking part in this study afforded me opportunities to learn about the intervention so that I could be prepared for the study in Chapter 5 and for future research. I also participated in a wider quantitative evaluation of the numeracy intervention, but these data will be included in another PhD student's thesis.

Chapter 2[1]: A Systematic Scoping Review of Social, Educational, and Psychological Research on Individuals with Autism Spectrum Disorder and their Family Members in Arab Countries and Cultures

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[1] Alallawi, B., Hastings, R. P., & Gray, G. (in press). A systematic scoping review of social, educational, and psychological research on individuals with Autism Spectrum Disorder and their family members in Arabic countries and cultures. *Review Journal of Autism and Developmental Disorders*.

Abstract

Cultural dimensions of autism spectrum disorder (ASD) are relatively unexplored in the research literature. The current study is a systematic scoping review describing social, educational, and psychological research focused on individuals with ASD and their family members in Arab countries and cultures. Seventy studies met eligibility criteria. Most of the studies were from Jordan, Saudi Arabia and Lebanon. Most of the identified research addressed three major domains: the prevalence of ASD and diagnosis issues, the experiences and outcomes for Arab caregivers of individuals with ASD, and social and communication behaviour of Arab individuals with ASD. There were significant gaps in research evidence base, including research on interventions and on ASD services. Overall, the included research was appraised as being of weak quality.

Introduction

In recent decades, prevalence estimates for autism spectrum disorder (ASD) have increased (Rice et al. 2012) with recent data suggesting an ASD prevalence in the United States of 1 in 59 children (Centre for Disease Control and Prevention, 2018) and 600,000 people, equivalent to a population prevalence of approximately 1%, in the United Kingdom (Buescher, Cidav, Knapp, & Mandell, 2014). In Arab countries, there are relatively few studies that have examined the prevalence of ASD (Hussein & Taha, 2014). However, existing studies do suggest that ASD is a prevalent disorder in Arab countries. For example, in the Sultanate of Oman, prevalence was estimated to be 1.4 cases per 10,000 children aged 0–14 years, with the highest prevalence among five to nine-year-old children, and in males (2.5 times the prevalence in females) (Al-Farsi et al. 2011). In Egypt, autism is often under-diagnosed or more frequently, misdiagnosed, and research suggests that there are more than 140,000 children in Egypt who are diagnosed with autism (Haffiz, 2007). In the United Arab Emirates (UAE), a representative random sample of 694 three-year-old children was assessed in a two-stage study in the community. In the first stage, using the Autism Screening Questionnaire, 58 per 10,000 children were noted to have autistic features. In the second stage using clinical interviews, the weighted prevalence was estimated to be 29 per 10,000 for a DSM-IV diagnosis of pervasive developmental disorder (Eapen, Mabrouk, Zoubeidi, & Yunis, 2007).

The Arab world comprises 22-member countries in the Middle East and North Africa: Iraq, Egypt, Syria, Jordan, Lebanon, Palestine, Qatar, Bahrain, Saudi Arabia, the United Arab Emirates, Oman, Somalia, Sudan, Mauritania, the Comoros Islands, Djibouti, Algeria, Morocco, Libya, Tunisia, Kuwait and Yemen; with a combined population of approximately 392 million people (World Bank, 2015). Although these countries share many similar characteristics in terms of their Arabic language and common Islamic religious backgrounds, they still vary enormously in terms of their political, ethnic, economic, social, and religious characteristics (Alkhateeb, Hadidi, & Alkhateeb, 2016; Taha, Hussein, & Almanasef, 2013). Accordingly, different opinions about the appropriate intervention and treatment of children with disabilities might be found in the Arab countries (Taha et al. 2013).

Each Arab country has its distinct individuality, with living and nutritional customs that could serve a protective or risk role in relation to developmental disorders (Hussein & Taha, 2014). Generally, Arab cultures are characterized by a higher rate of marriages among cousins, high support for nuclear families by their extended families, and therefore a high tolerance for taking care of individuals with disabilities, particularly children. Arab families may be more tolerant of behaviours in children that would be seen by Western communities as abnormal (Taha et al. 2013).

It could be argued, based on research such as that cited above, that the prevalence of ASD in Arab countries is lower than in the developed world. However, cultural factors may play a significant role in shaping some aspects of behaviour with respect to symptom recognition and response to the disorder (Taha et al. 2013). Moreover, it is often difficult to access diagnostic services for a child with ASD to be diagnosed precisely. In addition, parents prefer for their child to attend schools for typically developing children rather than being referred to special schools (Mostafa, 2011). Parents may under-report the child’s difficulties to assessors even though they are aware of them. In addition, paediatricians are relatively inexperienced in the diagnosis and management of psychiatric disorders compared to their Western counterparts. Therefore, both under-diagnosis and under–reporting due to paucity of awareness may play a role in the current variance in ASD prevalence between Arab countries and Western countries (Mostafa, 2011).

Although ASD occurs in all cultures and countries examined by researchers to date, the majority of research in the field of ASD has been conducted in Western countries. In contrast to Arab countries, Western countries typically have at least some and certainly more extensive professional support services (Hussein, Taha, & Almanasef, 2011; Sharpe & Baker, 2011). ASD was not a subject of study in the Arab world until the late 1990s (Hussein et al. 2011; Hussein & Taha, 2013). As a result, only small amounts of research have been conducted on ASD in the Arab world (Al-Salehi & Ghaziuddin, 2009).

Four recently published literature reviews have been conducted on ASD research in Arab countries (Alkhateeb et al. 2016; Alnemary, Alnemary, & Alamri, 2017; Hussein & Taha, 2013; Salhia, Al-Nasser, Taher, Al-Khathaami, & El-Metwally, 2014). Hussein and Taha (2013) conducted a review of the literature to gather all available studies published on ASD in Arab countries and summarized them to highlight which areas of research need to be addressed in future. The authors reviewed all published English language studies and their reference lists using a limited search strategy in only one electronic database. There was no systematic attempt to evaluate the methodological quality of the included studies. The authors indicated the difficulty in accessing studies that came from different national journals in different Arab countries and restricted their review to only internationally published studies. Overall, Hussein and Taha (2013) reviewed 75 studies, published from 1992 to 2012, which addressed different fields of ASD research such as genetic, autoimmune, oxidation stress, nutritional deficiencies, environmental toxins, errors of metabolism, mitochondrial dysfunction, clinical studies, imaging, treatment outcome and available services. Most of the studies (n=55, 73.3%) were published in the later years of the review period 2008-2012. The most addressed issue was possible etiologies of autism (n=42, 56.6%), while treatment outcome was the least addressed issue (n=4, 5.3%). Hussein and Taha (2013) indicated that most of the research was published in Saudi Arabia (n=23, 30.6%) and Egypt (n=16, 21.3%), while 11 studies (14.7%) came from Lebanon. The authors recommended organizational efforts to support ASD research to identify efficient strategies for improving diagnosis and service delivery to individuals with ASD and their family members.

Salhia et al.'s (2014) review aimed to evaluate the current state of knowledge on the epidemiology of ASD in Arab Gulf countries: Kuwait, Qatar, Saudi Arabia, the Sultanate of Oman, Bahrain, and the UAE. The authors reviewed all published English language studies on ASD epidemiology using a limited search strategy in two electronic databases. Salhia et al. (2014) clearly described their inclusion criteria. However, their methods for data extraction were not described. Furthermore, there was no systematic attempt to evaluate the methodological quality of the included studies. Two authors did independently extract data from included studies. The authors reviewed 12 studies, published up to 2013, three of which were prevalence studies that showed a prevalence ranging from 1.4 to 29 per 10,000 persons. The remainder of the included studies reported potential risk factors or biomarkers for autism in individuals from Arab Gulf countries.

Alkhateeb et al. (2016) conducted a comprehensive review of English language studies on the inclusion of children with developmental disabilities in Arab countries. Seven electronic databases were covered, and reference lists searches were used in searching the literature from 1990 to 2014. AlKhateeb et al. (2016) clearly described their inclusion criteria and their methods for study selection and data extraction.

However, there was no systematic attempt to assess the methodological quality of the included studies. The authors independently extracted data from included studies using a specifically designed data extraction form. Alkhateeb et al. (2016) reviewed 42 studies about the inclusion of children with developmental disabilities in Arab countries. Results revealed that more than two-thirds of these studies were from researchers in the UAE, Jordan, and Saudi Arabia. The majority of these studies were published in the six years up to 2014.

Finally, Alnemary et al. (2017) reviewed English language literature on ASD in the Arab world between the years of 1992 and 2014. Five electronic databases were used in searching published, unpublished, and grey literature. The authors examined how much ASD research has grown, where ASD research is being conducted, what ASD research areas are being addressed, what the impact of ASD research publications is, and who funds the ASD research. Inclusion criteria, methods for study selection, and data extraction were clearly described. However, there was again no systematic attempt to assess the methodological quality of the included studies. Alnemary et al (2017) identified 142 publications which addressed the biology of ASD (34.5%), risk factors (28.9%), and diagnosis (14.1%). The average number of country-specific publications per year was reported as 5.7 articles. ASD research was conducted in 13 Arab countries. The majority of studies were conducted in Saudi Arabia (n= 56), Egypt (n= 44) and Oman (n= 17). Several publications were published in journals with an impact factor ≥ 5.0. Over one third of the publications included funding acknowledgments. The majority of funding sources were governmental agencies (n= 53), whereas little research was funded by private organizations (n= 9). The authors recommended that additional research is needed to address fields involving developing screening and diagnostic tools, examining the efficacy of behavioural interventions, examining the effects of policies and resources on current services provided, studying lifespan issues, and surveillance.

The existing reviews have contributed to the knowledge base on ASD research in the Arab world. However, there are a number of methodological weaknesses in these reviews, including an absence of conducting comprehensive data-based searching and quality assessment of included studies, and reviewing only English language literature. At present, there is no systematic review concentrating on social, educational, and psychological (as opposed to medical/biological) research focused on individuals with ASD and their family members in Arab countries and cultures. The main purpose of the present study was to identify and synthesize the literature about social, educational, and psychological research conducted on individuals with ASD and their family members in Arab countries and cultures by mapping what is known about these areas, and also to include comprehensive data-based searching and quality appraisal of studies. In order to address the study purpose a scoping review was conducted. According to Moher, Stewart, and Shekelle, (2015) scoping reviews provide an overview of a broad topic. Consequently, a scoping review is an appropriate methodology for this study as it focused on broad topics including social, educational, and psychological research.

A scoping review is one form of reviewing available published literature on a given topic (Gough, Thomas, & Oliver, 2012). The use of a scoping review (as opposed to other methodologies such as a traditional systematic review with a meta-analysis) allows for a more general question and exploration of the related literature, rather than focusing on providing answers to a more limited question (Moher et al., 2015). Therefore, a scoping review attempts to provide an overview of a potentially large and diverse body of literature pertaining to a broad topic, whereas a systematic review seeks to collate empirical evidence from a relatively smaller number of studies pertaining to a focused research question (Arksey & O'Malley, 2005). According to Pham et al (2014) a scoping review provides for more flexibility than traditional systematic review and meta-analysis. It is able to incorporate a variety of relevant literature and studies utilising different methodologies, which is less feasible in a traditional review. However, a scoping review might be conducted as a first step in a larger project, such as a systematic review, descriptive research endeavour, or randomized trial. It can serve as a richly informed starting point for further investigations to understand and contribute to research, education, practice, and policy (Arksey & O'Malley, 2005).

In this scoping review, the following questions are addressed:

- What social, educational, and psychological research has been conducted on individuals with ASD in Arab countries and cultures?
- What social, educational, and psychological research has been conducted on family members of individuals with ASD in Arab countries and cultures?

Methods

A protocol was written for the review and this was followed throughout the procedures described below (see Appendix A, p. 301).

Search Strategy

Systematic searches were conducted in April 2016 (updated December 2017), starting with electronic searches of eight databases: PsycINFO, MEDLINE, ERIC, Social Science Citation Index, EBESCO, EMBASE, Web of Science and Google Scholar. The search included terms for ASD combined with search terms for Arab countries' names and their recognised abbreviations. The search terms below were searched in all fields.

(Autis* OR ASD OR Asperger* OR pervasive developmental disorder*'' OR PDD) AND (Arab* OR Algeria* OR Egypt* OR Libya* OR Tunisia* OR Morocco* OR Mauritania* OR Sudan* OR Somal* OR Djibouti* OR Bahrain* OR Emirates OR UAE OR Oman* OR Kuwait* OR Qatar* OR Saudi* OR KSA OR Yemen* OR Jordan* OR Syria* OR Iraq* OR Gaza OR Leban* OR Comoros* OR ''West bank'' OR Gulf OR ''Middle East''). A comprehensive multi-point search strategy was designed to ensure that, by the end of the search process, all relevant literature was found. This strategy included electronic searches of eight databases, previous systematic reviews and literature reviews, and forwards and backwards citation searching for all included studies.

A total of 667 references were identified through the initial search process after the first reviewer removed duplicate articles (Figure 2.1). Based upon title and abstract screening, two reviewers (first and third researcher) excluded 593 studies (interrater reliability 93%) as they clearly did not meet the inclusion criteria (e.g. not specifically about ASD, not about Arab countries and cultures). The two reviewers independently applied the inclusion criteria to the remaining 74 studies after obtaining full text copies. Of those 74 studies, 31 were excluded because they did not meet inclusion criteria. The remaining 43 studies were selected by the two reviewers to be included in the review. Further, hand searches were carried out to identify publications that had not been included and indexed by electronic databases or articles from journals that were not indexed by electronic databases. In addition, hand searches can compensate for inaccurate database indexing that can result in even the most carefully constructed strategy failing to identify relevant studies (Centre for Reviews and Dissemination CRD, 2009). Therefore, hand searches of reference lists used Google Scholar's 'cited by' feature for all included studies were carried out alongside checking of the reference lists of previous systematic reviews and literature reviews. These processes identified an additional 46 studies for consideration, and the two reviewers agreed to include 15 of these additional studies. The first reviewer searched the reference lists and checked citations of the additional 15 studies to identify more relevant studies for possible inclusion, resulting in an additional three studies, two of which were finally included. On checking the reference lists and citations of these final two studies, no more new relevant studies were found. To ensure that no recent papers were missed, the first reviewer repeated the database searches in December 2017, identifying 47 additional studies for consideration. Of those 47 papers, 10 studies were included. Ultimately, 70 studies met the inclusion criteria described below.

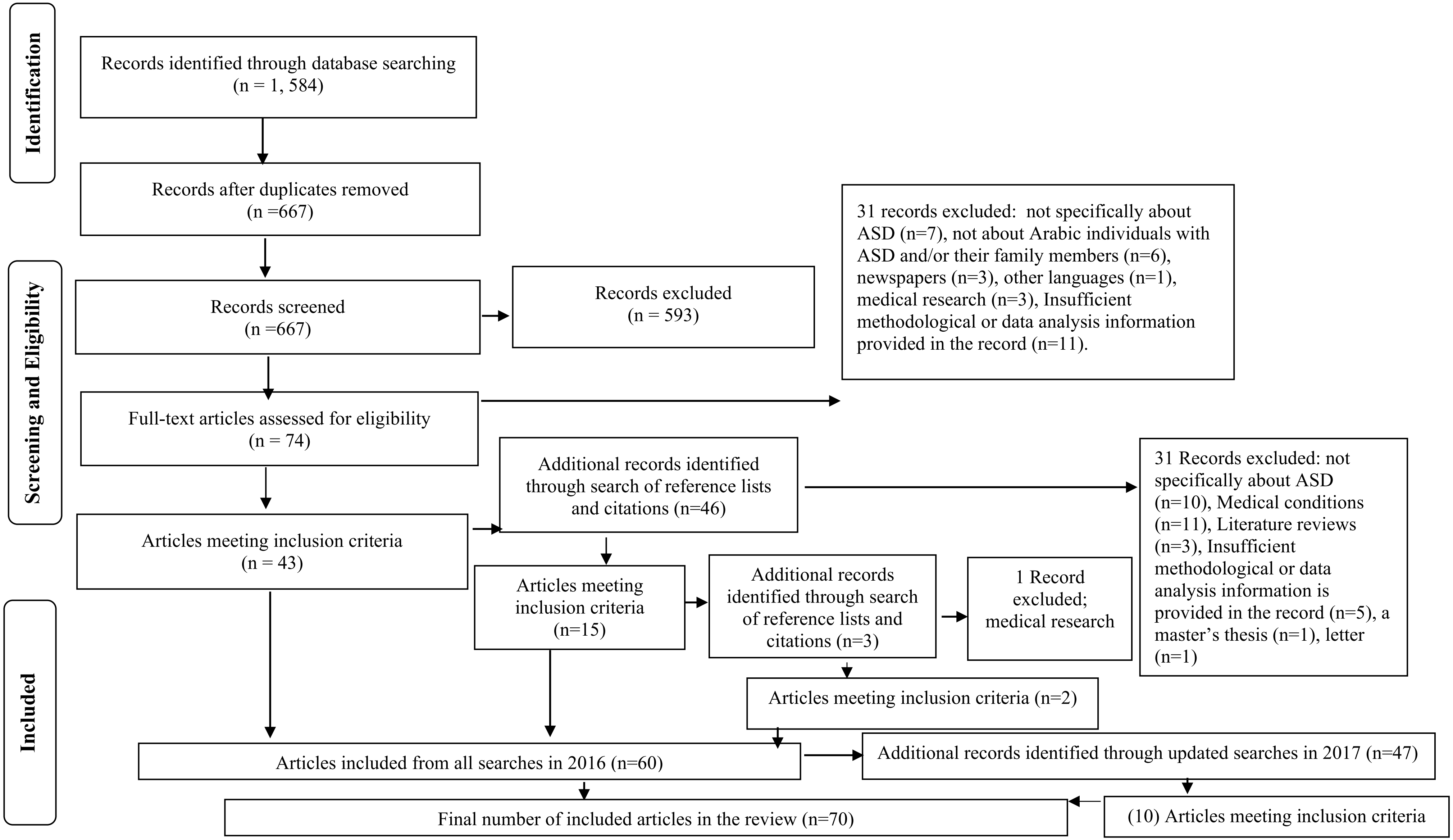

Figure 2. 1 A flow diagram of study selection process (adapted PRISMA 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' flow diagram)

Study Selection

To be included within the review, an article had to meet the following criteria: (a) studies had to adopt any research design or methodology (including case series, and case studies) and report research data; (b) the study had to focus on: social (research that focuses on people and societies exploring patterns of social relationships, social interaction, social phenomena, events, issues, problems, and culture that surrounds everyday life), educational (research that focuses on a variety aspects of education and learning processes such as individual learning, teaching methods, and/or classroom dynamics), or psychological (research that focuses on behaviour and mind of individuals including perception, emotion, experiences, feeling, thought, motivation, and/or personality) issues; (c) participants in studies had to be Arab individuals with ASD or their family members; and (d) studies had to have been published in the English or Arabic languages.

Studies were excluded from the review for the following reasons: (a) medical studies of individuals with ASD and/ or their family members including studies of medical causes (e.g. genetic factors, environmental factors, and metabolic disorders), medical diagnosis (e.g. biological markers such as immune blood markers, immune urine markers and laboratory tests such as genetic test, blood and urine test), medical treatment (e.g. dietary treatment, drugs, and acupuncture therapy), and physical health condition problems (e.g. food and skin allergies, vitamins deficiency, and gluten sensitivity); (b) systematic reviews; (c) the studies were published in a research thesis, books, book chapters, meeting abstracts or conference papers; and (d) the paper included insufficient methodological or data analysis information to understand the findings of the study.

Data Extraction and Appraisal of Study Quality

Each identified study was first assessed for inclusion/exclusion. After this, each included study was summarised by the first reviewer in terms of: (a) study reference (authors, publication date, and country where the study was conducted); (b) aims, study designs, and methods; (c) participants; and (d) results. The data extraction form was independently checked by the third researcher on a sample of included studies (20%) to verify the accuracy and completeness of the relevant data. The two reviewers agreed fully on all data extraction.

Quality appraisal tools were used for each type of study design included in the review. Three assessment tools were applied to included studies. The Critical Appraisal Skills Programme (CASP) tool was used for qualitative studies. This tool includes three broad dimensions that need to be considered when appraising a qualitative study: the validity of the study, the usefulness, and the importance of study findings (CASP 2014).

The Quality Assessment Tool for quantitative studies, which was developed by the Effective Public Health Practice Project (EPHPP) (2007) in Canada was used for all quantitative studies in the review. This tool includes the following component ratings: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity, and analysis. For Single Case Experimental Designs (SCEDs), the Quality Indicators tool developed by Horner et al. (2005) was used. This tool includes several critical features that can be used to assess different aspects of SCEDs, including information on description of participants and settings, dependent variable, independent variable, baseline data, experimental control/internal validity, external validity, and social validity (Wang & Parrila, 2008).

The third researcher independently quality assessed a sample of 20% of included studies from the searches originally conducted in April 2016 (10 quantitative studies, one qualitative study and one SCED study). Disagreements were resolved by consensus between the two reviewers (interrater reliability was 97%). Data were summarised using a narrative synthesis approach, due to the heterogeneity of the literature and study designs.

Results

Seventy studies were found on social, educational, and psychological research including Arab individuals with ASD and their family members in the following Arab countries: Saudi Arabia, Kuwait, Bahrain, Jordan, Lebanon, UAE, Oman, Egypt, Qatar, Libya, Iraq, West Bank, Syria, Tunisia. A small number of studies (n= 12, 17%) were conducted in non-Arab countries but with Arab populations (Baker, 2017; Barnevik-Olsson, Gillberg, & Fernell, 2008; Esler, Hall-Lande, & Hewitt, 2017; Estrem & Zhang, 2010; Dolev, Sher-Censor, Baransi, Amara, & Said, 2016; Fox, Aabe, Turner, Redwood, & Rai, 2017; Kediye, Valeo, & Berman, 2009; Meiri et al. 2017; Perepa, 2014; Raz, Weisskopf, Davidovitch, Pinto, & Levine, 2015; Sher-Censor, Dolev, Said, Baransi, & Amara, 2017; Walker-Dalhouse & Dalhouse, 2015). None of the 70 studies identified were published in Arabic.

The included studies were all published in or after 2007. Most of these studies (n= 50, 71%) were conducted between 2012 to 2017. Most of the studies were from Jordan (n= 14, 20%), Saudi Arabia (n= 10, 14%) and Lebanon (n= 5, 7%). All the studies that have been published from Jordan focused on Arab caregivers of individuals with ASD. In Saudi Arabia, the largest proportions of publications addressed Arab caregivers of individuals with ASD, followed by ASD prevalence and diagnosis issues and then the social/communication behaviour of Arab individuals with ASD. While in Lebanon, ASD prevalence and diagnosis issues was the most addressed topic.

Of the 70 studies, 59 were quantitative studies, seven were qualitative studies, one SCED study, and three case studies. Cross-sectional designs predominated. Questionnaires were the most common data collection method, while few studies used personal interviews or telephone interviews. Few studies evaluated interventions with a focus on individuals with ASD or their family members. Four studies evaluated social interventions for children with autism (Al-Shammari, Daniel, Faulkner, & Yawkey, 2010; Alshurman & Alsreaa, 2015; Al zyoudi, Sartawi, & Almuhiri, 2015; Fteiha, 2016) and two studies evaluated psychological interventions. Rayan and Ahmad (2016) evaluated the effectiveness of mindfulness-based interventions on perceived quality of life (QoL) and positive stress reappraisal among parents of children with ASD. El bahnasawy and Naglaa (2011) evaluated the outcomes of a counselling program for mothers to cope with their autistic children. The 70 studies targeted the following populations: 54% were families (parents/ caregivers), 43% were children with ASD, and 3% were adults with ASD.

Included studies focused on research addressing three major themes: (1) the prevalence of ASD and diagnosis issues, (2) the experiences and outcomes for Arab caregivers of individuals with ASD, and (3) social and communication behaviour of Arab individuals with ASD. The research in each of these three theme areas is summarised below. Detailed synthesis of findings is not included given the rated low quality of research in general (and thus the potential for mis-leading conclusions).

Prevalence of ASD and Diagnosis Issues

There were 23 studies that examined the prevalence of ASD or diagnosis issues in Arab countries and cultures (Table 2.1).

Table 2. 1 Prevalence of ASD and diagnosis issues

Study Reference and country	Aims, study design and methods	Participants	Results
Esler1et al, 2017. Minnesota	**Aims**: examine differences across racial/ethnic groups in ASD symptoms, cognitive and adaptive skills, and related behaviours in children with ASD that included a unique subgroup, children from the Somali diaspora. **Design**: Retrospective cohort study. **Methods**: Educational and medical records were used to identify Somali children. Case identification of ASD involved screening and abstraction, included the review of educational records for all children born in 2001, 2002, and 2003 who had ever received special education services and the review of clinic source health records in primary clinics where assessment, diagnosis, and treatment of various developmental disabilities (including ASD) occur.	Children who were age 7–9 years and who had one parent or legal guardian living in the city of Minneapolis in the calendar year 2010. Somali children represented 8.2% of the overall population of Minneapolis 7–9-year-olds.	Somali children were more likely to have ASD with intellectual disability than children from all other racial/ ethnic groups. Few differences were found in the presence of specific symptoms and behaviours across groups once IQ was controlled. Results lend support to previous studies that found higher rates of ASD intellectual disability in children of immigrants from low human resource index countries compared to other groups.
Chaaya et al, 2016. Lebanon.	**Aims**: assess the prevalence of ASD in children in nurseries in Beirut and Mount-Lebanon. **Design**: cross-sectional. **Methods**: Modified Checklist for Autism in Toddlers. Small structured questionnaire was	998 children from both genders and all ethnic groups, aged 18–30 months going to (177) nurseries.	ASD prevalence was 1 in 66 children (comparable to US). The male to female ratio was 1.05 (1 in 65 for males and 1 in 67 for females). The Beirut to Mount

Study Reference and country	Aims, study design and methods	Participants	Results
	developed and included characteristics of the children (birth weight, vaccines, age at first word, frequency of visiting a pediatrician, history of being diagnosed with autism); factors related to pregnancy and delivery, and socio-demographic and behavioural characteristics of the parents (education level, occupation, and family history of mental health problems).		Lebanon ratio was 1.2 (1 in 57: Beirut and 1 in 68: Mount Lebanon).
Mohamed et al, 2016. Egypt.	**Aims**: (in its stage I) aims at early screening of Egyptian toddlers for ASD using an Arabic validated version of Modified Checklist for Autism in Toddlers. **Design**: cross sectional community based descriptive. **Methods**: Retrospective revision of selected toddlers’ full medical history. Arabic validated version of Modified Checklist for Autism in Toddlers was used to screen the ASD risk. Failure of Modified Checklist for Autism by toddlers enrolled in stage I of this study meant that those toddlers who	6000 Egyptian toddlers were randomly recruited from those attending Primary Health Care Units in six Egyptian governorates. By exclusion of toddlers with known chronic physical illnesses and/or handicaps and those whose caregivers refused to share in the study, 5546 Egyptian toddlers were left. The included toddlers’ ages ranged between 1 to 2.9 years, 2830 were males	Failure of M-CHAT in 1320 out of the enrolled 5546 Egyptian toddlers (23.8%). Of those, 990 were males (75%) and 330 were females (25%); with male to female ratio of 3:1, while 1840 of those who passed Modified Checklist for Autism were males (43.54%) and 2386 (56.46%) were females. Consanguinity rate was significantly higher among toddlers who failed Modified Checklist for Autism (45%)

Study Reference and country	Aims, study design and methods	Participants	Results
	failed it are suspected to have ASD and need further evaluation by trained professionals.	(51.03%) and 2716 were females (48.97%).	compared to toddlers who passed it (31.97%); P = 0.0469, while there was no significant difference between toddlers who passed and failed Modified Checklist for Autism regarding frequency of family history of social and or communication problems.
Mohammed, 2016. Saudi Arabia.	**Aims**: detect ASD cases within the High-Risk Neonatal Follow Up Program, as an indicator of the prevalence of ASD and associated risk factors in the KSA. **Design**: cohort. **Methods**: Retrospective medical chart review in a tertiary care hospital in Riyadh. All children in the High-Risk Neonatal Follow Up Program were screened for developmental disorders at the corrected age of 18 and 36 months. Children who were diagnosed with ASD in the High-Risk Neonatal Follow Up Program were referred to the	All children admitted to the High-Risk Neonatal Follow Up Program were seen at 3 years corrected age between January 2012 and December 2013.	In 2012, 59 children were evaluated in the programme. Three cases were diagnosed with ASD, with an ASD incidence rate of 5.1% (95% confidence interval calculated by adjusted Wald method: 1.2-14.5%). In 2013, 48 children were evaluated, and 2 cases were diagnosed with ASD, with an ASD incidence rate of 4.2% (95% CI: 0.4%-14.8%). The total ASD incidence rate during

Study Reference and country	Aims, study design and methods	Participants	Results
	Comprehensive Autism Program, for further assessment and recommendation. Diagnosis of ASDs was based on DSM IV criteria.		the 2-year study period was 4.7% (95% CI: 1.7%-10.8%). Factors associated with a higher likelihood of ASD were: male gender, low birth weight, and gestational age less than 33 weeks.
AlAyadh et al, 2015. Saudi Arabia.	**Aims**: determine the early warning signs of ASD as perceived by parents of children with autism attending special private schools and as part of the Autism Research and Treatment Centre at the King Khalid University Hospital in Riyadh between December 2012 to March 2013. **Design**: case control. **Methods**: Questionnaire was designed and consisted of two parts. The first part included questions about the general health status of parents, labour, delivery and breast-feeding of the child, and family socioeconomic and education status. The second part included items about the child's behaviour in his/her	141 children, 57 ASD cases were selected, using convenience sampling method (49 boys and 7 girls) with Mean age= 9 years (SD=5), and 84 controls were randomly selected during well-baby check-ups in a primary baby healthcare clinic and matched with cases by gender, age, race, and socioeconomic status (43 boy and 38 girls) with Mean age= 5 years (SD=4).	loss of shared enjoyment with family members, absence of early speech symbols, e.g. stringing sounds together, loss of eye to eye contact between the child and others and lack of imaginative play are early warning signs of ASD by the age 12 to 18 months in Saudi children with ASD.

Study Reference and country	Aims, study design and methods	Participants	Results
	first 18 months of life as perceived by the parents or caregivers.		
Raz et al, 2015. Israel	**Aims**: present ASD incidence and its time trends for the total population of children born in Israel 1992–2009 and followed until the end of 2011, and to examine the differences in incidence by the major Israeli population groups. **Design**: retrospective cohort. **Methods**: Data was analysed from the Israeli National Insurance Institute. ASD incidence was calculated for all children born in Israel 1992–2009, and by population groups.	All children (n=2,431,649) born in Israel 1992–2009, whose mother was an Israeli resident. Three population groups were compared: Ultra-Orthodox Jews 28%, Israeli Arabs 18%, General Population 54%.	Overall, 9,109 ASD cases among 2,431,649 children were identified. ASD cumulative incidence by age 8 years increased 10-fold during 2000–201, while other child disabilities in Israeli National Insurance Institute increased only 1.65-fold. There was a consistent increase in ASD incidence with advancing birth cohorts born 1992–2004, stabilizing among those born 2005–2009. Incidence among Israeli Arabs starts to rise steeply only for birth cohorts 2002–2009, reaching a peak of 0.29 % at cohort age 2 for children born in 2009 - Israeli Arabs at cohort age two increased 37-fold within 10

Study Reference and country	Aims, study design and methods	Participants	Results
			years (1999–2009) and fivefold within the last 2 years (2007–2009).
Dirani & Salamoun, 2014. Lebanon.	**Aims**: describe demographic and clinical variables that are in play in the first assessment of children with ASD or IDD in a mental health clinic in Beirut Lebanon. **Design**: cohort. **Methods**: Charts of children visiting the child development clinic for a period of two years were reviewed. Checklist was designed to collect demographic information. Autism Diagnostic Observation Schedule were used to diagnose autism and to determine its severity level. The Wechsler battery of tests. Two categories of variables possibly affecting the early diagnosis of ASD or IDD were assessed: first, demographic variables (birth order, parental marital status, number of children in the family, area of residence, and family-related childhood adversity). Second, clinical variables (age at diagnosis, presence of a medical condition, chief	209 children between the ages of 1 and 12 years who have been clinically diagnosed with either ASD or IDD.	Children with IDD significantly reported higher rates of family-related childhood adversities (29%) than children with ASD (13.8% for ASD) ($p = 0.007$). The two groups did not differ in parents' marital status, birth order, and residence. Children with ASD seem to present for clinical assessment at a younger age (4.7 years) than children with IDD (7.5 years) ($p < 0.001$). The chief complaint upon first visit for clinical assessment differed significantly between the two groups ($p<0.001$). About two-thirds of children with IDD presented for cognitive problems,

Study Reference and country	Aims, study design and methods	Participants	Results
	complaint: behavioural problems, cognitive problems or communication problems, family history of neurodevelopmental disorders, source of referral, and severity of the condition).		one-third for behavioural problems, and none for communication problems. Children with ASD presented with communication problems (72.5%) and the remaining for behavioural (11.9%) or cognitive (15.6%) problems.
Akoury-Dirani et al, 2013. Lebanon.	**Aims**: present the psychometric properties of the Lebanese version of the Childhood Autism Rating Scale Second Edition, High Functioning Version. **Design**: cross sectional. **Methods**: Forward and backward translation of the Childhood Autism Rating Scale Second Edition, High Functioning Version. and the Childhood Autism Rating Scale Second Edition.	30 children and adolescents (24 with diagnosis of AD or PDD-NOS and 6 with a diagnosis of ADHD) aged 6–18 years were recruited from the Child and Adolescent Program at the American University of Beirut-Medical Centre, and a private child psychiatry clinic.	The Lebanese Childhood Autism Rating Scale Second Edition, High Functioning Version has a high degree of internal consistency (.92), inter-rater reliability (.97), and test–retest reliability (.99). This instrument can be used in screening and assessing for ASD in high-functioning Lebanese and Arab speaking individuals.

Study Reference and country	Aims, study design and methods	Participants	Results
Al-Ansari & Ahmed, 2013. Bahrain	**Aims**: estimate the prevalence of autistic disorder in Bahrain, together with the sex distribution and possible associated factors such prenatal and postnatal complications, type of delivery and other personal and familial characteristics. **Design**: case–control. **Methods**: Medical records from the Child and Adolescent Psychiatric Unit and social records from participating centres were reviewed and related data were abstracted. The data were entered into a form that aimed to collect data on child's age and sex, birth order, language development, sleeping and eating patterns, and on the mother's pregnancy and delivery, including duration of pregnancy, type of delivery, and any prenatal, natal and postnatal complications and stressful life events around the time of delivery. The parents' section included age at birth of the child, educational level, employment, family history of autistic disorder, consanguinity (1st or 2nd degree) and any history of psychiatric or	100 cases attending the units, the Alwafa centre, Al Rashad centre and youth club, who received a diagnosis of autistic disorder over the time period 2000–10, and 100 controls were children and youths receiving a diagnosis of nocturnal enuresis (n = 64), mild behaviour disorder (n = 10) and no psychopathology (n =26). They were randomly selected from a pool of 350 individuals matched for age (in 5-year age groups), sex, social class, parent's education and family history.	Prevalence of ASD was estimated as 4.3 per 10, 000 population, with a male: female sex ratio of 4:1. More than three-quarters of parents had received either high school or college education (77% mothers and 82% fathers). A family history of ASD was present in 12% of the studied families. (7%) of families reported the presence of psychiatric disorders among parents compared with 12% with chronic physical disorders. The majority of cases (85%) came from lower social classes. ASD cases had a significantly higher incidence of delivery complications (24% versus 12% for controls). In addition, 15% of mothers of ASD cases had

Study Reference and country	Aims, study design and methods	Participants	Results
	medical disorders. Social class was constructed following Hollingshead and Redlich’s scale.		prenatal complications compared with 4% control cases (OR = 4.19, 95% CI: 1.34–13.1) (P = 0.014).
Al-Zahrani A, 2013. Saudi Arabia.	**Aims**: determine the prevalence and describe the clinical characteristics of ASDs in school-age children. **Design**: cross sectional. **Methods**: The study proceeded in four steps: screening, sampling, and diagnostic assessment. All parents and teachers asked to complete the Autism Spectrum Screening Questionnaire.	All children born from 1999 through 2004 (ages 7–12 years at screening) and attending Taif elementary schools.	The overall prevalence of autism in the primary school of Taif district whose age ranged from 7 to 12 years was 0.035 % from a sample population of 22950 student, the prevalence of autism in male (0.031%) was greater than female (0.004%). The general characteristic of autistic disorders present in the sample population was concentrated on certain items mainly, has a different style to communicate with others, either formally or informally (80 %), deal with others with his own style (80%).

Study Reference and country	**Aims, study design and methods**	**Participants**	**Results**
Hamadé et al, 2013. Lebanon.	**Aims**: investigate the association of autism with several risk factors which include parental age, sex, maternal unhappy feeling during pregnancy, consanguineous marriage, and province of residence. **Design**: case-control. **Methods**: Questionnaire consisted of three parts: socio-demographic characteristics, characteristics of the child, and finally health characteristics of parents.	86 autism cases from specialized schools for children with DD in all Lebanese regions except for the South, and 172 controls were randomly selected from lists provided by ten non-specialized public schools administrators, age-matched and taken from the same regions as the corresponding cases.	Significant association between autism and older parents age (OR=1.27), male sex (OR=3.38), unhappy maternal feeling during pregnancy (OR=5.77), living close to industry (OR=6.58), previous childhood infection (OR=8.85), but none concerning maternal age, paternal age and consanguinity.

Study Reference and country	Aims, study design and methods	Participants	Results
Taha et al, 2013. Saudi Arabia & Egypt.	**Aims**: examine and compare the outcome of autism in a sample of Egyptian and Saudi patients from a comprehensive point of view over a period of 2 years and identify factors and prognostic variables related to outcome. **Design**: comparative prospective naturalistic. **Methods**: Clinical Global Impression – Improvement Scale. Childhood Autism Rating Scale. Gilliam Autism Rating Scale. Vineland Adaptive Behavioural Scale. Stanford Binet intelligence quotient test. Assessment at baseline and at follow-up after 2 years.	48 children with autism (20 Egyptians and 28 Saudi) were recruited from the Institute of Psychiatry, Ain Shams University, Cairo, Egypt, and the Al-Amal complex for Mental Health, Dammam, Kingdom of Saudi Arabia.	Good outcome among the entire sample was significantly correlated with higher age of noticing abnormality, higher intelligence quotient, mild severity of autism, fairly high scores on the Vineland scale, and low stereotypy scores. Good outcome among the entire sample was also significantly associated with having atypical autism, absence of seizures, normal milestones of development, high parental concern, having normal electroencephalography, taking no drugs or being stable on one drug therapy, early behavioural intervention, receiving phoniatric therapy, and improvement of more than two core deficits in response to drug therapy.

Study Reference and country	**Aims, study design and methods**	**Participants**	**Results**
Amr et al, 2012. Egypt, Saudi Arabia, & Jordan.	**Aims**: examine the influence of sociodemographic variables on the severity of autistic symptoms and behavioural profile in Arab children. **Design**: cross sectional. **Methods**: Diagnosis of ASD was based on DSM-IV criteria. Arabic version of the Wechsler Intelligence Scale for Children. Stanford Binet Intelligence Test. Semi-structured questionnaire was used and included various demographic and academic characteristics including age, gender, educational status of the child, parental educational and occupational status, family size, and income. Arabic version of the Indian Scale for Assessment of Autism. Arabic version of the Child Behavior Checklist.	60 children (38 boys and 22 girls) with a diagnosis of ASD who were recruited from three centres: Centre for Early Diagnosis of Children´s Disabilities, Amman, Jordan (22 children), child psychiatry settings in Mansoura University Hospital, Egypt (19 children) and Al-Ahsa psychiatric Hospital, Saudi Arabia (19 children).	Sixty percent of the children were diagnosed with at least one comorbid disorder. The most commonly reported comorbid disorders were anxiety disorders (58.3%), ADHD (31.6%), conduct disorders (23.3%), and major depressive disorder (13.3%). Out of the total sample, Obsessive compulsive disorder was the most prevalence anxiety disorder (55%). Elimination disorders were also diagnosed in 40% of children.
Amr et al, 2012. Jordan, Egypt, & Saudi Arabia	**Aims**: estimate the prevalence of comorbid psychiatric disorders in a sample of children with ASD and examined the relationship between comorbidity and children's cognitive functioning and gender. **Design**: cross sectional. **Methods**: Arabic version of the Indian Scale for	60 children (37 boys and 23 girls) diagnosed with ASD were recruited from specialized centres in three Arab countries: centre for early diagnosis of children's disabilities, Amman Jordan (n = 22), child psychiatry	Most commonly reported comorbid disorders were anxiety disorders (58.3%), ADHD (31.6%), conduct disorders (23.3%), and major depressive disorder (13.3%). Children with comorbid psychiatric disorders

Study Reference and country	Aims, study design and methods	Participants	Results
	Assessment of Autism. Arabic version of the Wechsler Intelligence Scale for Children. Stanford Binet Intelligence Test. Clinical psychiatric interview was developed and included different modules which consisted of attention-deficit hyperactivity disorder, oppositional defiant disorder, conduct disorder, separation anxiety disorder, generalized anxiety disorder, obsessive compulsive disorder, and specific phobia, major depressive disorder and elimination disorders.	settings in Mansoura University Hospital, Egypt (n = 19) and Al-Ahsa psychiatric Hospital, Saudi Arabia (n = 19). Autistic disorder was diagnosed in 33 boys and 22 girls, the PDDNOS in four boys and only one girl.	were found to have significantly lower IQ (mean = 45.8 3.1) than those without comorbid psychiatric disorders (mean = 63.3 3.3; P = 0.03). There were no significant sex differences in rates of any disorder (49% males vs. 56% females, P = 0.39), anxiety disorders, ADHD, conduct disorder, major depression or elimination disorder (P value of 0.43, 0.46, 0.69, 0.57, 0.08, respectively).
Zeglam & Maound, 2012. Libya	**Aims**: estimate the prevalence of ASD in children attending the neurodevelopment clinic of Al-Khadra Hospital in Tripoli. **Design**: retrospective cohort. **Methods**: Screening of all children referred to the clinic between 2005 and 2009 with the diagnosis of delayed speech and language, no speech or language or behavioural difficulties. Children were reviewed,	180 children referred to the clinic between 2005 and 2009 with a diagnosis of speech and language disorders or behavioural difficulties.	There were 38, 508 children in total seen during 2005–09, 180 of whom had a history of delayed speech and language and/or behavioural difficulties. Of the 180, 128 children were diagnosed with ASD 99 had classical autism, giving the prevalence of

Study Reference and country	Aims, study design and methods	Participants	Results
	scored and classified as having ASD if they displayed behavioural abnormalities consistent with DSM-IV for diagnosing autism, (PDD-NOS), including atypical autism, or Asperger disorder.		about 4 in 1000. The male: female ratio for ASD was 4:1 and for autism was 4.5:1. The most common age at presentation was 2–5 years (58%) and 56% presented 6–18 months after the onset of symptoms.
Al-Farsi et al, 2011. Oman.	**Aims**: assess the prevalence of ASD among 0–14-year-old children in Oman. **Design**: cohort. **Methods**: Arabic-language questionnaire on sociodemographic variables such as age, gender, nationality, level of parents' education, place of residence, family income, and occupation of parents. Standardized and validated Arabic version of the Childhood Autism Rating Scale questionnaire.	Children aged 0-14 year who had been formally diagnosed with an ASD. Cases were identified from all hospitals and social institutions that offer targeted services to ASD, including one tertiary hospital with a child psychiatry unit and 8 social centres for children with special needs.	A total 113 cases of ASD were enumerated nationwide, indicating an overall prevalence of 1.4 (95% CI 1.2, 1.7) cases per 10,000 children aged 0–14 years. More prevalent cases were among boys (75%) and among low-income families. Ritualistic interests were more common among girls as an onset-symptom compared to boys ($p = 0.03$).
Amr et al, 2011. Egypt, Saudi Arabia, & Jordan.	**Aims**: address sex differences in autistic symptoms and coexisting behavioural problems and explore sex differences in coexisting psychopathology by parents	37 boys and 23 girls (ratio of 1.6:1) with ASD who age (from 4 to 11) years were recruited	No statistically significant child sex differences on any demographic characteristic,

Study Reference and country	Aims, study design and methods	Participants	Results
	of the studied children. In addition to present a comprehensive, descriptive profile of the socio-demographic characteristics of the studied children and their families. **Design**: cross sectional. **Methods**: Socio-demographic questionnaire was used with parents includes (age, nationality, educational and occupational status of both parents, level of income, family size). Clinical interview based on DSM-IV-TR criteria. Indian Scale for Assessment of Autism was used for identification and rating the severity of autism. Arabic version of Child Behavior Checklist.	from the Centre for Early Diagnosis of Children's Disabilities, Amman, Jordan (22 children), child psychiatry settings in Mansoura University Hospital, Egypt (19 children) and Al-Ahsa psychiatric Hospital, Saudi Arabia (19 children).	including child and parent age, nationality, educational and occupational status of both parents, level of income, family size. Boys had a significantly higher level of poor emotional responsiveness than girls and girls had significantly more cognitive problems than boys. Boys exhibited significantly more delinquent behavior and the girls more sexual problems.

Study Reference and country	Aims, study design and methods	Participants	Results
Hussein et al, 2011. Egypt & Saudi Arabia.	**Aims**: understanding and comparing the demographic background, clinical characteristics and presentations of autism as well as comparing methods of examination and intervention with this condition in both Egyptian and Saudi children. **Design**: comparative. **Methods**: Clinical assessment sheet for symptoms of autism and associated symptoms such as hyperactivity, regression, seizures, and comorbid psychiatric conditions. Assessment sheet for family factors (parents' education and work, patient education, family history of related disorders and family concern for autism). Assessment sheet for perinatal events, birth order and developmental factors. Sheet for detailed intervention and management. Arabic version of Gilliam autism rating scale. Arabic version of Stanford Binet test. Vineland Adaptive Behavioural Scale.	48 children with ASD (Egyptian group n= 20 and a Saudi group n= 28) of both sexes and with age ranging from birth up to 18 years. They were recruited from the Okasha Institute of Psychiatry, Ain Shams University, Cairo, Egypt and Al-Amal Complex for Mental Health, Dammam, Kingdom of Saudi Arabia.	Delayed language development was significantly higher in the Egyptian group while delay in all developmental milestones was more significant in the Saudi group. The age at diagnosis and at the commencement of intervention was lower in the Egyptian group. The Saudi group showed a higher percentage of missing examinations, older birth order and significantly higher preference to drug treatment, while the Egyptian group showed a high preference to behavioural and phoniatric therapies, higher paternal and maternal education, higher employment among parents and higher family concern.

Study Reference and country	Aims, study design and methods	Participants	Results
Raddad et al, 2011. Jordan	**Aims**: examine the contributions of demographic variables (age, gender, socioeconomic variables) and intellectual correlates among a sample of Jordanian children with AD. **Design**: cross sectional. **Methods**: DSM-IV-TR diagnosis of autistic disorder was assigned in each child by a clinical interview based on DSM-IV–TR criteria. Semi-structured questionnaire includes various demographic and academic characteristics. Arabic version of the Indian Scale for Assessment of Autism. Arabic version of Child Behavior Checklist. Jordanian version of Wechsler Intelligence Scale of Intelligence.	22 children referred to the Early Diagnosis of Children's Disabilities EDCD centre in Jordan for symptoms related to AD.	A significant main effect of gender for the emotional responsiveness and behavior patterns subscales of ISAA, the delinquent behavior and social problems subscales of Child Behavior Checklist. The interaction between education and socioeconomic status was statistically significant for the social relationship and reciprocity Indian Scale for Assessment of Autism subscales and social problems, attention problems, aggressive behavior subscales and total Child Behavior Checklist. IQ was significant for social relationship and reciprocity, speech-language and communication, sensory aspects, cognitive component subscales of

Study Reference and country	Aims, study design and methods	Participants	Results
			Indian Scale for Assessment of Autism and the withdrawn, somatic problems, social problems, thought problems, attention problems and aggressive behavior subscales of Child Behavior Checklist.
Estrem & Zhang, 2010. Minnesota.	**Aims**: explore trends in prevalence rates of children who received autism special education services between 2001 and 2008, with a focus on students whose home language was not English. **Design**: retrospective cohort. **Methods**: Data was used from the Minnesota Department of Education for the academic years 2001-2008 for individual students who receive special education services. Students were categorized as speakers of English as a primary language, or English language learners classified into the three predominant primary languages in Minnesota- Spanish, Somali, and Hmong - or other primary languages.	All children aged between birth to 21 years in Minnesota public schools and those receiving special education under the autism categorical label between 2001 and 2008.	Dramatic increase over the past decade in prevalence rates of all children with autism. Autism prevalence for Somali increased at a more dramatic rate (to 9.2 per 1000 children than for English (14.7), Spanish (4.4), Hmong (2.6), or between English language learners groups. Distinct differences among the various home language groups and the ages at which they first received autism services. The mean age of entry was significantly lower than

Study Reference and country	Aims, study design and methods	Participants	Results
			the English primary language group for Somali (6.46 years, p < .0001), Spanish (8.64 years, p < .0001), and Other (8.94 years, p < .0001), but not for Hmong children (10.0 years, p = .06).
Barnevik-Olsson et al, 2008. Stockholm county, Sweden.	**Aims**: investigate the prevalence of autism in children with parents from Somalia, living in Stockholm, and to compare the prevalence in children of Somali background with that in the non-Somali group. **Design**: cohort. **Methods**: All records of children in the age group with a Somali background, who were registered at either one of the two habilitation centres and who had a diagnosis of autistic disorder or PDDNOS, were reviewed, and their status as regards Somali background was determined. All records were scrutinized regarding antenatal, perinatal, and postnatal data, medical information, and data from the assessment supporting the diagnosis of autism.	All children aged 7–17 years (birth years 1988–1998) who have been given a diagnosis of autistic disorder or PDDNOS according to DSM-IV, in conjunction with learning disability are referred for intervention and follow-up to one of two autism habilitation centres (‘north’ and ‘south’).	A total of 501 children (with a male: female ratio of 3:1) had a diagnosis of AD or PDDNOS. 17 (13 males, 4 females, population-adjusted male: female ratio 3.3:1) of the 501 children with AD (n=14) or PDDNOS (n=3; 3.4% of all with AD or PDDNOS) had a Somali background. The minimum prevalence of AD or PDDNOS was 0.7% (17 of 2437; 95% confidence interval 0.37–1.03) among children with a Somali background. Among the children with a non-Somali

Study Reference and country	Aims, study design and methods	Participants	Results
			background the corresponding prevalence was 0.19% (484 of 250 565; 95% CI 0.18–0.21; p<0.001).
Seif Eldin et al, 2008. Egypt, Kuwait, Jordan, Lebanon, Oman, Qatar, Saudi Arabia, Syria, & Tunisia.	**Aims**: determine the feasibility of using the Modified Checklist for Autism in Toddlers to assess autism in Arab countries with a limited assessment and mental health resources and describe some socio-demographic data on ASD in the countries represented in the Arab world. **Design**: cross sectional. **Methods**: Modified Checklist for Autism in Toddlers. Members of the Eastern Mediterranean Association of Child and Adolescent Psychiatry and Allied Professions from Egypt, Iraq, Saudi Arabia and Tunisia translated the tool into Arabic. A child failed the checklist when two or more of the critical items were failed or when any three items failed.	228 children (122 screened positive for ASD) were recruited from Egypt, Kuwait, Jordan, Lebanon, Oman, Qatar, Saudi Arabia, Syria and Tunisia. The number of boys (n=185) exceeds that of girls (n=43) by more than four times. The number of children recruited from different countries ranged from 8 to 82 with age range 18 to 124 months. The control group was selected from typically developed children matched by age and sex.	Final analysis included 228 children, 122 cases screened positive for the presence of ASD (84% boys and 16% girls), with a mean age of 43.1 21.4 months (range: 18 to 124 months) and 106 controls with typical development matched for age and sex provided from eight out of the nine countries. The sensitivity (0.86), the specificity (0.80) and positive predictive value (0.88). Maternal health problems during pregnancy and labour were found to be more significant for ASD mothers than their control. In addition, child health problems

Study Reference and country	Aims, study design and methods	Participants	Results
			were more evident among ASD subjects as reported by their parents with significant differences from controls.
Eapen et al, 2007. United Arab Emirates.	**Aims**: estimate the prevalence and correlates of PDDs in preschool children in the UAE. **Design**: cross sectional. **Methods**: Two-stage were implemented: First stage, Autism Screening Questionnaire was carried out, Denver Developmental Screening Test was used to identify global developmental delay, and Child Behaviour Checklist 2–3 years was used for the evaluation of behavioural problems. Second stage, a semi-structured interview was used to obtain sociodemographic information and other family factors.	694 three-year-old children was evaluated in a two-stage study in the community.	The weighted prevalence of PDD for the entire population was estimated to be 29 per 10 000 (95% confidence interval=0–0.79%). There was a significant association with male gender, family history of developmental delay and presence of behavioural problems, other factors including parental education and occupation, socioeconomic status, family composition and parental consanguinity were not found to be associated with autistic features.

Of those 23, four studies were conducted in non-Arab countries but with Arab populations (Barnevik-Olsson et al. 2008; Esler et al. 2017; Estrem & Zhang, 2010; Raz et al. 2015;). The total number of Arab participants included in these studies was 916. There were six collaborative studies conducted across the Arab countries. Arab countries that contributed to this area of research were: Lebanon, Jordan, Oman, UAE, Bahrain, Libya, Egypt and Saudi Arabia. The total number of participants for studies in this area of research was 43,846. Most of the studies used samples from hospital and specialist units that offer services for children with special needs. For example, Al-Farsi et al. (2011) recruited a sample of children aged 0-14 years from all hospitals and social institutions that provide targeted services to ASD patients in Oman, including one tertiary hospital with a child psychiatry unit and eight social centres for children with special needs distributed in all regions in the country. Results revealed that the overall prevalence of ASD was found to be 1.4 cases per 10,000 children. The male to female ratio was 3:1. Further, in Libya, of 38,508 children seen in the neurodevelopment clinic of Al-Khadra Hospital in Tripoli, 128 children were diagnosed with ASD: 99 (55%) children had classic autism, 21(12%) had pervasive developmental disorder not otherwise specified, 6 (3%) had Asperger syndrome and 2 (1%) had Rett syndrome. The prevalence of ASD was 1 in 332 children seen at the pediatric outpatient department, approximately 3 per 1000 children (Zeglam & Maouna, 2012).

Other studies attempted to determine the prevalence of ASD in samples from preschools. For example, in Lebanon, a sample of 998 children from both genders and all ethnic groups, aged 18– 30 months were recruited from 177 nurseries in the capital city, Beirut and Mount Lebanon by using the Modified Checklist for Autism in Toddlers (M-CHAT). Results revealed that ASD prevalence was 1 in 66 children. The male to female ratio was 1.05 (1 in 65 for males and 1 in 67 for females) (Chaaya, Saab, Maalouf, & Boustany, 2016).

There were few studies that attempted to validate screening and diagnostic tools for use in Arab countries. A recent study from Lebanon (Akoury-Dirani, Alameddine, & Salamoun, 2013) employed forward and backward translation of the English version of Childhood Autism Rating Scale Second Edition, High Functioning Version (CARS2-HF) into Arabic and evaluated its psychometric properties. It was reported that the Lebanese version of the CARS2-HF had a high degree of internal consistency, inter-rater reliability, and test–retest reliability. These data suggest that the CARS2-HF can be used in screening and assessing for ASD in high-functioning Lebanese and Arab speaking individuals (Akoury-Dirani et al. 2013). A study was also conducted in nine Arab speaking countries aiming to validate the Modified Checklist for Autism in Toddlers (M-CHAT) as an Arab tool for the screening of autism. The analysis included 228 children (122 of whom screened positive for ASD). Results indicated that the new translated M-CHAT is an effective tool to use in the early screening of autism in Arab countries. Maternal health problems during pregnancy and labour were more significant for ASD mothers than for controls. Pediatric health problems were significantly more evident among ASD individuals than among controls (Seif Eldin et al. 2008).

There were few studies comparing issues related to ASD diagnosis across two or more Arab countries. For instance, Amr et al. (2011) investigated autistic symptoms and coexisting behaviour problems in 37 boys and 23 girls with ASD from three Arab countries (Egypt, Saudi Arabia, and Jordan). Results indicated that boys had poor emotional responsiveness and the girls had more cognitive problems. Boys exhibited significantly more delinquent behaviour problems. Another study by Hussein et al (2011) compared characteristics of autism in two groups of 20 Egyptian and 28 Saudi children with respect to demographic and clinical characteristics. Results revealed that there was no difference of statistical significance between the two groups in type of autism. Hyperactivity was found in 50% of Egyptian children in comparison to 60.7% of Saudi children. Further, epilepsy was found in 25% of Saudi children versus 5% of Egyptian children. Psychiatric comorbidities were reported in 71.4% of Egyptians and 67.5% of Saudi children. Egyptian autistic children were characterised by delayed language development, earlier age at start of treatment intervention, high preference for behavioural and phonetic therapies, higher paternal and maternal education, higher employment among parents, and higher family concern. In contrast, the Saudi group were characterised by delay in all developmental milestones, severe and profound communication defects, more stereotypes and developmental deficits, younger age at detection of abnormality and older age at start of treatment intervention, with a marked difference between the two (being around two years), higher percentage of missing examinations, older birth order, and significantly higher preference for drug treatment (Hussein et al. 2011).

Experiences and Outcomes for Arab Caregivers of Individuals with ASD

Arab caregivers of individuals with ASD were the focus of 37 studies, 53% of the included research (Table 2.2).

Table 2. 2 The experiences and outcomes for Arab caregivers of individuals with ASD

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Al-Kandari, 2017. Kuwait	**Aims**: provide a general profile and describe coping strategies of families of children with ASD in Kuwait, focusing specially on mothers. **Design**: cross-sectional. **Methods**: A questionnaire was designed. It contains three sections with 24 questions in total. The first section asked about background information, such as the mother's age, nationality, and education level. The second and third sections included questions about the child with ASD and family management, such as who is the primary caregiver of the child and how many hours does the mother spend with her child each day.	198 mothers of children with ASD enrolled in 21 special needs schools registered with the Public Authority of the Disabled.	The majority of mothers reported decreased ability to perform social duties (62.4%) and take care of themselves (50.5%). Overall, 57.7% of mothers reported a decreased ability to enjoy life. There was a significant association between the mothers' ability to enjoy life and receiving support from the family (p value=0.021) and support groups (p value=0.003). 'Religion', 'Acceptance', and 'Positive Reframing' were the 3 most common coping strategies.
Al-Dababneh et al, 2017. Jordan	**Aims**: address in considerable depth the beliefs of parents of children with ASD, ID, and SLD about the causes of these disabilities, as well as their beliefs about the ability of their children to make progress in either mainstream schools or segregated centres.	63 parents of children aged 6–15 all of whom had mild to moderate levels of ASD, ID or SLD.	Disabilities were attributed to supernatural and biomedical causes; also, most parents had positive expectations about their children's progress, especially in

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	Design: Qualitative. **Methods**: Semi-structured interviews were designed by the researchers in order to guide the interviews. A series of open-ended questions was used to encourage discussion around a number of themes, including beliefs regarding the causes of disability and expectations about their children's likelihood of making progress, in line with the literature.		education skills, and had hopes for their children's futures.
Alnemary et al, 2017. Saudi Arabia	**Aims**: identify what services children with ASD receive, what is the average age at treatment initiation, and what child, family, and service characteristics are associated with use of ASD services. **Design**: cross- sectional. **Methods**: an online survey was developed on the basis of previous studies that examined factors associated with the use of ASD services. The survey included information about the family, the child with ASD and two additional measures: Parental Concerns Questionnaire was used to indicate to which each core and Behavioural Symptom of autism has been a problem for their child. Autism Knowledge	205 parents of children with ASD.	On average, children began services by 3.3years. Most parents reported utilizing non-medical treatments followed by biomedical treatments and cultural and religious treatment. The age at the initiation of services and the type of treatments used differed by parent's income, educational attainment, the extent of knowledge about autism spectrum disorders, and

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	Questionnaire was used to assess parents’ knowledge about etiology, diagnosis, and specific features of ASD.		geographic location. Some child characteristics also influenced the use of services.
Baker, 2017. United States	**Aims**: examine the language-development-related knowledge and beliefs of paired mothers and educators of three Somali American boys with autism **Design**: case study **Methods**: semi structured interview was developed, which addressed beliefs and knowledge related to language recommendations for students with autism in multilingual environments, among other topics.	3 mother/ educator pairs. Each mother is a Somali American mother of a boy with autism, and each educator is the boy’s primary teacher as defined by the mother. Participants were recruited through contacts at local educational, health, advocacy, and other agencies that support Somali families.	Five distinct themes emerged from this study: (a) individuals with autism benefit from exposure to multiple languages, (b) the belief that multilingualism can be confusing for individuals with autism, (c) families value home language exposure, (d) educators are uncertain about providing language recommendations, and (e) information about students’ multilingual context is virtually absent from educational documents and Individualized Education Program meetings.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Eid et al, 2017. Saudi Arabia	**Aims**: evaluate the extent to which parents of children with ASD learn skills from observing other parents being taught using Behavioural Skills Training model. **Design**: experimental. **Methods**: using a multiple probe. Parents were specifically scored based on the following for each trial: 1) sit facing the child; 2) allow the child to briefly sample the toys; 3) tell the child to choose one of the items; 4) prevent access to the items; 5) provide an action model with the item chosen by the child for 5 s; 6) parent models a vocalization while modelling an action; 7) repeat model; 8) reinforce relevant responses; 9) repeat relevant phrases during the play interval; 10) Parent says my turn and then implements the next trial.	6 parents were recruited through a centre for education and research in ASD in a large city in Saudi Arabia.	All of the parents who observed the model learned from observing other parents being trained directly. The parents demonstrated maintenance of their skills at follow-up, and social validity evaluations were strong.
Fox et al, 2017. United Kingdom	**Aims**: assess what Somali families affected by autism need, and how health, education and social care services can support them. **Design**: qualitative. **Methods**: a semi- structured interview-based approach was selected. Interviews lasted 45–95 min and	15 parents. 12 were female and three were male and all were from separate families. Their average age was 36 years. Between them the participants had	Two themes are reported; ‘Perceptions of Autism’ and ‘Navigating the System’. This research shows the importance of understanding cultural views of autism and the need to raise

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	explored family's experiences of having a child with autism, from the first time they became aware of their child's difference, through the process of diagnosis and their subsequent experiences of health, social and education services.	17 children with a diagnosis of autism.	awareness, reduce stigma and provide support to encourage families not to delay seeking help for their children
Hemdi & Daley, 2017. Saudi Arabia	**Aims**: evaluate the efficacy of a self-help psychoeducation intervention with minimal therapists' support and delivered via WhatsApp. **Design**: randomized two-arm controlled trial with two conditions (mothers in the intervention group vs. mothers in the care as usual) and three-time points (Pre- intervention [T1], post intervention [T2], and an 8-week follow-up [T3]). **Methods**: The intervention consisted of one face-to-face session (60 min) and four virtual sessions (30 min each) delivered using WhatsApp. Parenting stress was the primary outcome, with secondary outcomes focusing on maternal depression, anxiety, and happiness, and child behaviour problems and ASD symptoms. Data were collected at baseline T1, immediately post intervention T2 and 8-week follow-	62 mothers (23–52 years) of children (26–78 months) were recruited to multisite randomized controlled trials of the intervention	One-way analysis of covariance was used at T2 and T3 with T1 scores entered as a covariate. Improvements were found at T2 for stress (F = 234.34, p = .00, and d = −1.52) and depression (F = 195.70, p = .00, and d = −2.14) but not anxiety, and these results were maintained at T3. Changes in child behaviour problems were limited to improvements in hyperactivity at T2 (F = 133.66, p = .00, and d = −1.54). Although changes in stress and depression were statistically significant, change

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	up T3. Measures were used: Parents' demographic questionnaire was used to collect information about participants. Parent Stress Index Short Form was used to measure the stress associated with parenting. Hospital Anxiety and Depression Scale was used to determine the level of anxiety and depression. Strength and difficulties questionnaire was used to identify behavioural problems in children. The Indian Scale for Assessment of Autism was used to measure the severity of autism. The Arabic Scale of Happiness was used to measure happiness in adults.		to clinically normal levels was limited to depression.
Sher-Censor et al, 2017. Israeli	**Aims**: examine the interplay of mothers' coherent representations of their child; resolution of the child's ASD diagnosis; and emotional availability to the child in the unique cultural context of Arab-Israeli families. **Design**: cross-sectional. **Methods**: The Five-Minute Speech Sample was used to assess the coherence of mothers' representations of their child and their relationship, mothers were audio-recorded while speaking for 5 uninterrupted minutes about their child. Reaction to Diagnosis Interview was	46 mothers and their 2–8-year-old sons. The child had to have a previous established ASD diagnosis; in the age range of 2–8 years; residing at home; and not have any known medical problems. All mothers were married. Forty families were Muslim	coherent and resolved mothers were more emotionally available than incoherent and/or unresolved mothers. These findings highlight the importance of supporting mothers' ability to accept the child's diagnosis and see the unique characteristics of the

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	used to evaluate mothers' resolution of their child's ASD diagnosis. The Emotional Availability Scales was used to assess the observed emotional climate of the parent–child interaction in terms of parental sensitivity, structuring, lack of intrusiveness and lack of hostility, and child responsiveness and involvement. The Vineland Adaptive Behavior Scales was used to assess adaptive behaviours. Demographic Questionnaire was used to report family and child characteristics, health status, and economic stress.	(87.0%), five were Christian (10.9%) and one was Druze (2.2%).	child beyond his ASD symptoms.
Dolev et al, 2016. Israel	**Aims**: examine maternal resolution of the child's diagnosis, and its associations with Arab-Israeli mothers' sensitivity to the child, maternal psychological distress, parenting stress, social support, and family demographics. **Design**: cohort. **Methods**: Reaction to diagnosis interview was used to report parents' feelings and thoughts about their child's diagnosis. Maternal sensitivity scale was used to assess maternal sensitivity and reflects mother's responsiveness to the child's signals and expression of	A sample of 46 mothers and their 2–8-year-old sons who were diagnosed with ASD. Included only boys in order to minimize within-group variability and because the ratio of ASD in the population is 4 boys to 1 girl. All mothers were married. Forty families were Muslim (87.0%), 5	Maternal sensitivity was observed during two mothers–child play contexts, didactic and social play. Resolved mothers reported lower psychological distress and less parenting stress. Resolved mothers were also more sensitive to their children during social play than unresolved mothers. Yet, there were no significant differences

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	warmth and emotional connectedness to the child. Social Communication Questionnaire, a short version of the Autism Diagnostic Interview was used to assess mother's perceptions of their children's ASD related symptoms. Vineland Adaptive Behavior scales was used to assess adaptive behaviours in the domains of socialization, communication and daily living skills. Brief Symptom Inventory was used to measures psychological symptoms. Family Impact Questionnaire was used to ask mothers to compare themselves and their sons to other parents and children in their age. Family Support Scale was used to measure ten sources of informal support, and eight sources of formal support that parents have found useful in rearing the young child with a disability during the last six months. Demographic questionnaire was used to report family and child characteristics, economic stress and health status. All questionnaires were translated to Arabic.	were Christian (10.9%) and 1 was Druze (2.2%). Of participating children, based on the Vineland Adaptive Behavior Scales, 45 (97.8%) were found to have a low level of adaptive behavior, while only 1 (2.2%) child had a high level.	between resolved and unresolved mothers neither in their reports of informal and formal social support nor in their sensitivity to child during didactic play.
Rayan & Ahmad, 2017. Jordan	**Aims**: assess psychological distress in parents of children with ASD and examine the potential	187 parents of children with ASD were recruited in	Parental age and gender were found to predict parental stress,

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	correlation between positive stress reappraisal coping and psychological distress in Arab parents of children with ASD after the influence of some parental characteristics were controlled. **Design**: cross sectional. **Methods**: Arabic version of Depression, Anxiety and Stress Scale was used to measure the severity of depression, anxiety and stress. The Positive Reappraisal Coping Subscale of the Cognitive Emotion Regulation Questionnaire was used to measure cognitive coping strategies that a person uses after experiencing negative life situations. Socio-demographic questionnaire was used to obtain demographic characteristics of parents and their children with ASD.	coordination with 10 centres serving children with ASD in Jordan. Out of the 187 parents invited, 104 completed the study measures.	but not parental anxiety and depression. The small sample size in relation to the number of the independent variables could contribute to the non-significance of parental age and gender to predict parental anxiety and depression in the regression model. However, positive stress was found to predict psychological distress in parents regardless of parent's age or gender. Increase in Positive Reappraisal Coping was associated with a decrease in parental distress. Positive Reappraisal Coping is stronger predictor of psychological distress in parents than parental age or gender.

Study Reference and country	**Aims, Study Design and Methods**	**Participants**	**Results**
Rayan & Ahmad, 2016. Jordan	**Aims**: examine the effectiveness of Brief Mindfulness-Based Interventions on perceived quality of life and positive stress reappraisal among parents of children with ASD. **Design**: quasi-experimental, with non-equivalent control group. **Methods**: Demographic survey was developed to obtain socio-demographic variables of participants and their children with ASD. World Health Organisation Quality of Life Assessment- Brief was used to measure QoL. Arabic version of positive stress reappraisal subscale of the Cognitive Emotion Regulation Questionnaire was used to measure coping strategies that a person uses after experiencing negative life situations. Arabic version of Mindful Attention Awareness Scale was used to measure trait mindfulness.	104 parents of children with ASD were equally assigned to the intervention and control groups. Groups were matched on measures of their age and gender, and level of severity of ASD in children. The intervention group participated in the intervention for 5 weeks, while the control group had not attended the program. Most of parents had only one child with ASD (94.2%), five had two children with ASD, and one mother had three children with ASD.	Parents in the intervention group demonstrated significant improvements in measures of psychological health domain of quality of life, social health domain of quality of life, mindfulness, and positive stress reappraisal with medium to large effect size ($p< 0.01$). The control group showed improvement in measures of the dependent variables with small effect size.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Zaki & Moawad, 2016. Egypt	**Aims**: assess the influence of autism awareness on the psychological wellbeing of mothers caring for their children with autism. **Design**: cross sectional. **Methods**: A structured interviewing questionnaire was developed and concerned with the following items: Socio-demographic characteristics of mothers, Characteristics of children, and Mother's knowledge related to their awareness about their children's autism. Parents stress scale was developed to assess the extent of stress and burden on the parents' caring for children with autism. It consisted of 18 short statements and divided into 6 subscales: stress from child dependency, stress from child future, stress from family disharmony, stress from financial cost, stress from personal exhaustion. Psychological Well-Being Scale was used to assess the overall psychological well-being.	60 children (1-5 years) and their mothers (who give direct care to the child) and attended the Special Needs Care Centre in the Institute of post-graduate Childhood Studies which affiliated to Ain Shams University and the second one was the out-patient clinic for child psychiatric treatments at El Abassia mental health hospital.	About two thirds of the studied sample had poor awareness regarding autism and there was a highly statistical significant relation between awareness, stress and psychological wellbeing among mothers of children with autism.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Ahmad & Dardas, 2015. Jordan	**Aims**: develop the necessary understanding of the characteristics of fathers of children with ASD that can potentially predict their quality of life. **Design**: cross sectional. **Methods**: Arabic version for the Parenting Stress Index – Short Form with parents of children with ASD was used to measure stress associated with parenting. Arabic version of the World Health Organization Quality of Life Assessment –Brief Self-Administered Instrument for parents of children with ASD was used. Standard simultaneous regression was used for modelling the relationship between quality of life as a dependent variable and 7 independent variables (parental distress, parent–child dysfunctional interaction, difficult child characteristics, fathers' level of education, family income, child's gender, and child's age).	101 fathers of children with ASD.	Family income, child's age, and parent–child dysfunctional interaction was not significant predictors for the quality of life of fathers of children with ASD. However, the remainder of the variables added significantly to the explained variance of quality of life.
Dardas & Ahmad, 2015. Jordan	**Aims**: examine coping strategies as mediators and moderators between stress and quality of life among parents of children with autistic disorder **Design**: cross sectional.	184 parents of children with ASD. Parents were included in the study if they had a child under the age of	Accepting responsibility was the only mediator strategy in the relationship between stress and quality of life. Only seeking

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	Methods: Parenting Stress Index-Short Form was used to measure parenting stress. Revised Ways of Coping Checklist was used to identify which strategies parents use in cope with stressful encounters. World Health Organisation Quality of Life Assessment- Brief was used to measure quality of life.	12 years with a clinical diagnosis of ASD and they were able to read and write in Arabic.	social support and escape avoidance were moderator strategies in the relationship between stress and quality of life.
Obeid & Daou, 2015. Lebanon	**Aims**: examine the effects of coping styles, social support, and child's behavioural symptoms on the well-being of mothers of children with ASD and compare them with mothers of children of typical development. **Design**: case control. **Methods**: Five self-report scales were used for collecting data in the sample of mothers of children with ASD, assessing coping styles, perceived social support, child's behavioural problems, well-being, in addition to other demographic variables. Brief COPE Scale was used to assess coping strategies. Interpersonal Support Evaluation List was used. Indian Scale for Assessment of ASD was used to assess behavioural symptoms of the child with ASD. The	65 mothers of children with ASD and 98 mothers of children of typical development. Most of the mothers across both groups were married. Most of the participants had two children. Most of those in the ASD sample had a boy diagnosed with ASD (78.5%).	Disengagement and distraction coping predicted poor well-being, whereas cognitive reframing showed a correlation with better well-being levels. A significant correlation was found between child's behavioural problems and maternal well-being. T-test analyses revealed that mothers of children with ASD differed in terms of coping styles used. Mothers of children with ASD showed lower levels of perceived social support. Well-being was significantly

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	General Health Questionnaire was used to assess maternal well-being. A demographic questionnaire was used, containing information about the mother and the child. The General Health Questionnaire was used to assess maternal well-being.		better for mothers of typically developing children.
Abu-Hamour & Muhaidat, 2014. Jordan	**Aims**: investigate the attitudes of parents in Jordan towards the inclusion of students with (ASD) in public schools and explore whether variable demographic characteristics such as age, student's gender, parent's gender, education levels, monthly income, and high- or low-function ASD correlated with the parents' attitudes, and examine the parents' perceptions of the most important prerequisite child-based skills for successful inclusion of students with ASD. **Design**: cross sectional. **Methods**: A survey was developed and consisted of two main sections. The first section requested descriptive information and the second section requested information about the necessary skills for including students with ASD in public school.	148 parents of students with low and high function ASD were recruited from seven special-education centres or schools that specialised in teaching students with ASD. Most of the parents (95%) considered themselves to be middle income and they were married (92%). The age range for students with ASD was from 5 to 16 years.	About 49.3% (n =73) were of the opinion that students with ASD should have a chance to be included in public schools, while 50.7% (n= 75) were against the idea. The variables that correlated with parents' attitudes towards inclusion were education levels and high- or low-function ASD. Parents recommended the following prerequisite skills for successful inclusion in; dependent skills, playing skills, behavioural skills, imitation skills, routine skills, social skills, paying

Study Reference and country	Aims, Study Design and Methods	Participants	Results
			attention skills, language skills, and pre-academic and academic skills in that order.
Al Jabery et al, 2014. Jordan	**Aims**: investigate the perceptions and experiences of parents of children with autism regarding the current provided services in Jordan **Design**: cross sectional. **Methods**: Questionnaire was developed and consisted of five sections. The first section asked for demographic information about parents and their children. The second section consisted of eight services. The third section consisted of 12 different methods used by parents to locate the services for their children. The fourth section included 20 items using a five-point Likert scale that ranged from 'not very satisfied' to 'very satisfied' that asks parents to rate their satisfaction with the currently received services. The five section is used an open-ended question format asking parents to list what they perceived as needed services besides the current provided ones; to	60 parents of children with autism (5–18 years old) were recruited from four special education institutions in Jordan.	The service delivery system with which parents interacted was composed of multiple places and providers but had several difficulties. Parents expressed an average satisfaction with the received services. Issues pertaining to the cost of services, parents-professional partnerships, and overall quality of services were seen by parents as sources of low satisfaction. Parents expressed the need for early intervention, family counselling, and community awareness services.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	direct the attention toward any new types of services that might be needed for future considerations.		
Al-Khalaf et al, 2014. Jordan	**Aims**: investigate whether the provision of an education program in Jordan for mothers of children with ASD increased mothers' understanding of their child's behaviour, improved the mothers' coping skills, and reduced their stress levels. Further, identify whether there were substantial differences between Jordanian mothers' and fathers' stress and coping skills in families with a child with ASD. **Design**: cohort. **Methods**: Pre-intervention interviews were conducted, and the mothers were asked to answer the Coping Strategy Indicator Scale and the parent stress index short form. The education program was delivered to the 10 mothers. It consisted of four sessions, the first session provided an introduction and general information about the three major areas of impairment associated with ASD. The second session focused on communication difficulties in children with ASD, and social difficulties. The third session discussed	10 mothers of preschool age children with ASD and their marital partner, who, in all cases was the father of the child with ASD. The sample was recruited from two private centres for children with disabilities in Amman, Jordan and was randomly chosen (5 in each centre).	Following the education program, the mothers reported a statistically significant reduction in stress levels, an increase in coping skills, and an improvement in mother child interaction. Compared to fathers, mothers' stress levels were significantly higher, and their coping skills were significantly lower.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	repetitive behaviour and the problems with sensory processing faced by many children with ASD. The final session discussed strategies to help children with ASD during play time and also ways to manage children's' sleeping and eating problems. Post-intervention interviews were conducted one week after the completion of the program.		
Dardas & Ahmad, 2014. Jordan	**Aims**: examine the relationship between two sets of variables in a sample of parents of children with autistic disorder. The first set was composed of the parents' characteristics which include (parents' gender, age, education, income) and time since their diagnosis) and the coping strategies used. The second set was composed of three stress subscales-parental distress, parent-child dysfunctional interaction, and difficult child, And the parental quality of life. **Design**: cross sectional. **Methods**: Parenting Stress Index-Short Form was used to measure parenting stress. It has three subscales, each consisting of 12 items: Parental Distress; Parent–Child Dysfunctional Interaction; and Difficult Child.	184 Jordanian parents of children with autistic disorder. Of the 184 parents, 62% (n = 114) were mothers. The mean age was 37 (SD = 7.6) years. About 46% (n = 85) had a secondary school or lower level of education, 23.9% (n = 44) had a high school diploma, and 29.9% (n = 55) held a baccalaureate degree or higher; and nearly half	Parents who have higher incomes, use diverse problem-solving strategies, exhibit less escape-avoidance, and exhibit less responsibility acceptance behavior tended to report lower PD, PCDI, and DC scores and a higher quality of life score. Being an older parent, having more time since the child's autistic diagnosis, and using more distancing coping strategies were associated with lower Parental Distress scores,

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	Arabic version of the World Health Organization Quality of Life Assessment-Brief Self-Administered Instrument was used to measure quality of life. Ways of Coping Checklist-Revised was used to addresses coping strategies that used by individuals to deal with specific stressful events.	(56%) were not currently employed. Mean family income for participants was 498 Jordanian Dinars (SD = 294).	higher Parent–Child Dysfunctional Interaction and Difficult Child scores, and better quality of life.
Dardas & Ahmad, 2014. Jordan	**Aims**: examine differences in the quality of life quality of life between fathers and mothers of children with autistic disorder in a sample from an Arab country, and examine the psychosocial correlates of the quality of life of Arab parents of children with autistic disorder. **Design**: cross sectional. **Methods**: World Health Organization Quality of Life Assessment self-administered questionnaire was used to measure the quality of life. Arabic version of the Parenting Stress Index-Short Form was used to measure the stress associated with parenting. Ways of Coping Checklist-revised was used to indicate the parent's ways of coping to deal with stressful encounters.	184 parents of children with autistic disorder. Their mean age was 37 years (SD = 7.6) ranging from 21 to 57 for mothers and 25 to 69 years for fathers.	Fathers and mothers of children with AD showed no significant differences in their physical, psychological, social, and environmental health. Further, both parents showed almost similar bivariate correlations between the reported quality of life levels and their parenting stress, coping strategies, and demographic characteristics.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Dardas & Ahmad, 2014. Jordan	**Aims**: examine the possible mediation and moderation effects of coping in the relationship between fathers' of children with autism parenting stress and quality of life. **Design**: cross sectional. **Methods**: Parenting Stress Index-Short Form was used to measure fathers' perception parenting stress. Revised Ways of Coping Checklist was used to identify which strategies parents use in cope with stressful encounters. Arabic version of World Health Organisation Quality of Life Assessment- Brief was used to measure quality of life.	101 fathers of children with ASD, aged 25-69 years. Almost all were married (98%, n=99), and the majority had a secondary school or higher.	None of the investigated coping strategies could mediate or moderate the stress– quality of life relationship among the fathers.
Dardas & Ahmad, 2014. Jordan	**Aims**: examine the psychometric properties and the theoretical structure of the Parenting Stress Index-short form with Jordanian parents of children with autistic disorder. **Design**: cross-sectional. **Methods**: - Exploratory factor analysis was used to summarise data by grouping together variables that are inter correlated. Confirmatory factor analysis was used to necessitate the estimation and specification of one	184 parents of children with autistic disorder, 62% (n = 114) were females (mothers). The mean age for the sample was 37 years (SD 7.6) ranging from 21 to 69 years. All of the parents had only one child diagnosed with autistic	The modified three-factor model (30 items) fits the data significantly better than the 36-item model. The 12 items of the Parental Distress sub-scale support the original scale structure. However, items in the Parent–Child Dysfunctional Interaction and Difficult Child

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	or more hypothesised models of factors structure, each of which proposes a set of latent variables (factors) to account for covariance among a set of observed variables.	disorder. All of the children were clinically diagnosed with autistic disorder from board-certificated child psychiatrists using the DSM-IV criteria.	sub-scales did not show stability in their structure. The Parenting Stress Index-short form in its 30-item model has endorsed the necessary validity of the scale with parents of children with autistic disorder.
Dardas &Ahmad, 2014. Jordan	**Aims**: examine predictors of quality of life for fathers and mothers of children with Autistic Disorder. **Design**: cross sectional. **Methods**: Arabic version of Parenting Stress Index – Short Form with parents of children with ASD was used. It contained three distinct subdomains: (a) Parental Distress (b) Parent–Child Dysfunctional Interaction, and (c) Difficult Child. Arabic version of the World Health Organisation Quality of Life Assessment- BREF self-administered instrument was used to measure individuals' physical, psychological, social, and environmental health and considers individuals' overall perception of quality of life.	Fathers (N =70) and mothers (N=114) of children with AD. Mothers were the primary caregiver (84%) for children with AD.	Only Parental Distress was a significant predictor for both parent’s quality of life, whereas Difficult Child Characteristics, household income, and number of siblings were able to predict only mothers’ quality of life.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Dardas L, 2014. Jordan	**Aims**: investigate the psychosocial impacts of raising children with Autistic Disorder in a sample from the Arab world and examine the levels of parenting stress, the coping strategies, and the levels of quality of life reported by Arab parents. **Design**: cross sectional. **Methods**: Parenting Stress Index-Short Form was used to measure stress associated with parenting. Ways of Coping Checklist-Revised was used to identify strategies that people use to deal with the internal and/or external demands of specific stressful encounters. World Health Organization Quality of Life Assessment-Brief self-administered instrument was used to provide a short form quality of life assessment.	184 parents of children with AD. Parents were recruited through public and private Jordanian centres and associations that offer services for children with AD.	Parents of children with autistic disorder experience significant high levels of parenting stress. Positive reappraisal was the most frequently used coping strategy among those parents. Meanwhile, confrontive coping was the least frequently used strategy. In regard to parents' quality of life, parents reported poor physical, psychological, social, and environmental health scores, with mothers reporting relatively lower scores. The lowest scores for parents were reported on the environmental health domain.
Kareem & Ali, 2014. Iraq	**Aims**: assess quality of life domains of the parents of children who have autism in Erbil and compare the quality of life domains and items between parents. **Design**: cross sectional.	115 parents of children with ASD who ages between 3-20 years old and from both genders.	For fathers of children with autism there was a significant association between age and physical domains, level of

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	Methods: The Kurdish version of the World Health Organization Quality of Life - BREF was used. It consisted 26-item scale including four domains and two items as follows: Physical domain, Psychological domain, Social relationship domain and Environment domain.		education and environmental domain and also general health, occupational status and environmental domain. Highly significant associations were observed between fathers' socio-economic status and all other domains and items except social relationship domain. Conversely, mothers of children with autism demonstrated a highly significant difference between occupational status and environmental domain, a highly significant relationship between socio-economic status and environmental domains and overall quality of life.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Al-Farsi et al, 2013. Oman	**Aims**: assess whether caregiver's variations in socioeconomic status has direct bearing on challenges of nurturing children ASD in the urbanized population of Oman dwelling in the capital area, Muscat. **Design**: cross-sectional. **Methods**: A questionnaire was designed to explore the opinions of the caregivers of children with ASD regarding services. The questionnaire dealt with the caregivers' perception of remedial and rehabilitation services available in the country for their children, their utilization and perception of psychiatric services, constraints of being a caregiver of children with ASD, and the expenses involved in taking care of children with ASD.	150 caregivers who caring for children with ASD living in the urban area, the capital of Oman, Muscat from two types of socioeconomic status SES (low-income and middle-high income).	Of the 150 families surveyed, 70 (47 %) were low income and 80 (53 %) were middle- high income. About 60 % of the families reported that they were not satisfied with remedial and rehabilitation services dispensed to their children with ASD. The rate of attending psychiatric services was significantly higher among low income families compared to middle-high income families. In both low and middle-high income families, taking care of an autistic child consumes about 15.0 % of the family's monthly income. caring for children with ASD is a costly affair.

Study Reference and country	Aims, Study Design and Methods	Participants	Results
Almansour et al, 2013. Saudi Arabia	**Aims**: evaluate the presence of depression and anxiety in a group of parent of ASD children in comparison with a group of parents of normally developing children, and to determine the factors associated with depression and anxiety among parents and caregivers of autistic children (parental factors, child factors, and medical factors). **Design**: case control. **Methods**: A self-reported questionnaire was utilized containing 14 questions regarding demographic data, psychiatric history of parents. Arabic version of the hospital anxiety and depression scale.	100 parents, 50 parents of at least one child diagnosed with an ASD (cases) were recruited through the Saudi Charitable Society of Autism Families and the Autism Clinic in the Pediatric out-patient clinic in King Fahad National Guard Hospital, King Abdulaziz Medical City, and 50 Parents of a normally developed child (controls) were recruited from the Well Child Clinic at King Abdulaziz Medical City, Riyadh.	More than 50% of the control group was in the age group 26-30 years (56%), while 42% of cases were in the age group 31-35 years. Time lapsed since autism diagnosis was over 3 years in one-third of cases. 22% of cases, and only 2% of control parents/caregivers had a history of psychiatric problems ($p=0.002$). Both the mean depression score, and the mean anxiety score was significantly higher among cases when compared with controls, $p<0.001$.
Dababnah & Parish, 2013. West Bank	**Aims**: examine knowledge, attitudes, burdens and coping strategies related to caring for a child with ASD in the West Bank. **Design**: qualitative.	24 parents of children (up to age 18) with ASDs were recruited in 14 West Bank villages and refugee camps.	Parents struggled with financial stressors, child behavioural and medical challenges, and depression. Few parents were

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	Methods: Interview and focus group study was conducted. Each questionnaire contained a series of eight open-ended questions and related probes focused on parent stress, coping strategies, and the impact of the child's disability on the family, including the child's strengths and challenges.		aware of ASDs prior to their children’s diagnoses. Discrimination and stigma from extended family members and the larger community intensified parents' feelings of shame and experiences of social isolation. Some parents coped by withdrawing from the community or denying the diagnosis, other aimed to increase social interactions and access information. Religious coping was found to be partly adaptive for some of the participants.
Fido & Al Saad, 2013. Kuwait	**Aims**: evaluate the prevalence of parental depression in families of children with autism and in control families. **Design**: case control. **Methods**: Arabic translated version of the Beck’s	120 mothers and fathers of autistic children whose children were attending the Kuwait Autism Centre.	No significant difference was observed across the samples of fathers other than slight increase for the autistic group. Marital status did not affect the number

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	Depression Inventory was used. It consisted of 21 symptoms or attitudes commonly seen in patients suffering from depression (e.g. sadness, negative self-concept, sleep and appetite disturbances).		of mothers of the autism groups who had elevated depression scores, but single mothers in both groups had higher elevated depression scores than mothers living with partners, (x2 = 6.4, p < 0.005). Out of mothers with autistic children, 32.3% had depression and 41.5% had dysphoria while, 10% of control mothers had depression and 16% had dysphoria, x2 = 6.3 (p < 0.001).
Alqahtani, 2012. Saudi Arabia	**Aims**: evaluated qualitatively the beliefs of parents of children with autism in Saudi Arabia. **Design**: qualitative. **Methods**: A semi-structured interview format was used, and interview topic guide was designed to obtain open answers. The interview topic guide was elicited to include beliefs about autism, the causes and treatments choices. All questions were open, and	85 parents of children with autism. However, there were 15 parents, 11 mothers and 4 fathers, who refused to participate. As a result, a total of 47 parents, 22 mothers and 25 fathers participated. The age of the	Several causes of autism were reported. A vaccine was the most causative sources reported. Some parents feel guilty that they caused their children’s autism. Others believed that nonmedical or cultural reasons such as evil eye and black magic

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	parents were asked to express their beliefs as completely and deeply as possible.	parents ranged from 27–57 yr. More than half of the parents ranged between 33 and 40 year old. Parents were selected from King Fahad medical city.	could cause autism. Few parents reported using alternative medical intervention, such as diet program and hyperbaric oxygen therapy to heal their children from autism.
Kheir et al, 2012. Qatar	**Aims**: assess the concerns of caregivers of children with autism in Qatar regarding their child's life, future and care. **Design**: case control. **Methods**:- Demographic information related to the child's life at home were collected from both groups and included information related to the child (e.g. the child's date of birth, his/her relation to the caregiver, number of siblings, number of hours of sleep in a day, number of hours spent watching television or videos prior to age 3, time spent indoors prior to age 3, absenteeism from school, and use of a nanny to care for the child) and to the caregiver (education level, profession, level of consanguinity using the phylogram method). Caregivers were asked specific questions	56 caregivers of a child with ASD (Autistic Group AG) who was between the age of 3 to17 years old and were recruited from the two-main developmental pediatric and children rehabilitation clinics in Qatar. The control group consisted of 48 caregivers of a neurotypically-growing child (non-autism group NAG) was between the age of 3 to 17 years old and who were visiting a family	Children in the AG spent more time indoors, watching TV, or sleeping than children in the NAG. Only around 40% of the caregivers in the AG said they would encourage their child to get married and become parent when she/he grows up. Religious faith helps caregivers in accepting having a child with autism. A number of autistic caregivers usually use specialized rehabilitation services; other did express their needs for these services and

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	relating to maternal concern and considerations related to the future of their children and the specialized services they receive.	clinic of a primary health care facility for routine medical check-up.	made comments about having to wait long time before they were provided with some of the services.
Kheir et al, 2012. Qatar	**Aims**: investigate the impact of having a child with autism on the lives of the caregivers in Qatar. **Design**: case control. **Methods**: The Lebanese Arabic version of the Standard Recall Short Form 36 was used to assess the quality of life of caregivers. It addressed eight health-related domains: Physical Functioning, Social Functioning, Role limitations due to Physical problems, Role limitation due to Emotional problems, Mental Health, Vitality, Bodily Pain, and General Health. Further, demographic and other related information were collected from caregivers.	98 caregivers, 56 caregivers of a child with autism (AG) who was between the age of 3 and 17, and 42 caregivers of a typically developing child (NAG) who was between the age of 3 and 17and were visiting a family clinic of a primary health care facility for routine medical check-up.	No significant difference between quality of life domains between the two groups of caregivers, but caregivers of autistic children rated their health as poor and likely to get worse ($p < 0.05$). Caregiver gender appears to be associated with several quality of life domains ($p < 0.05$). Female caregivers suffered more bodily pain and had much more fatigue and tiredness (low vitality) than men ($p < 0.05$), and they had more problems with work or other usual activities as a result

Study Reference and country	Aims, Study Design and Methods	Participants	Results
			of emotional problems ($p < 0.05$).
Elbahnasawy & Naglaa, M. 2011. Egypt	**Aims**: evaluate the effect of counselling for mothers to cope with their autistic children, through: identifying mothers' needs according to physical, social, motor, and emotional coping patterns for their autistic children, and developing counselling program according to mothers' needs and evaluating the effect of counselling on physical, social, motor, and emotional coping patterns of mothers. **Design**: cohort (one group pre and post). **Methods**: Interviewing questionnaire to assess children's and their mothers' socio-demographic characteristics and mother's practices. Family Impact of Childhood Disability Scale was used to assess subjective interpretation or primary appraisal of parent regarding to child with developmental disabilities into family systems and its impact on the family as an entity. Medical records of the studied autistic children to determine the degree of disability.	90 mothers providing care for their children with autism. They were recruited from the Special Needs Care Centre in the Institute of Postgraduate Childhood Studies affiliated to Ain Shams University and Egyptian Autistic Society.	The children were completely dependent on their mothers in basic daily activities as bathing, elimination, wearing clothes; communication and holding pencil. A child with autism leads to substantial degree of impact on his family life and parent caregivers. Care of the autistic child brought family closer to God, additional financial costs, and needs for more effort and time. There was statistically significant improvement after the counselling program implementation for all aspects of coping patterns of mothers' care physical, social, emotional,

Study Reference and country	Aims, Study Design and Methods	Participants	Results
			motor, and communication skills for their autistic children.
Al-Eithan et al, 2010. Saudi Arabia	**Aims**: determine whether children with ASD/PDD more likely to have parents from maths or engineering educational backgrounds, than children with other developmental disorders. **Design**: case control. **Methods**: Data were gathered through personal contact, following extraction of all relevant data from the medical records. Data covered basic demographic information (gender, age, age at diagnosis, and consanguinity) in addition parents and grandparent's education and profession.	57 parents (all fathers) of ASD/PDD children and 40 parents of children with developmental disorders as a control; these included speech delay, mental retardation, and Down's syndrome.	A difference between the 2 groups regarding the (hypothesized engineering link), however this did not reach major statistical significance (x^2=2.503, df=1; p=0.093). Further, there was no significant difference (x^2=0.370; df=2; p=0.831) between the 2 groups on the variable of consanguinity.
Al-Kandari & Al-Qashan, 2010. Kuwait	**Aims**: identify the perception of maternal self-efficacy among Kuwaiti mothers of children with DD to determine the differences in perception of maternal self-efficacy variables among the mothers based on demographic variables: child's age, gender, type of disability, leisure time, and mother's age. **Design**: cross sectional. **Methods**: Demographic questionnaire was developed	95 mothers (between the ages of 21 and 59 years old) of children with DD in Kuwait. Of these mothers, 33 had children with IDD, 41 had children with DS, and 21 had children with autistic disorder. The	Mothers of children with DD did not differ in their beliefs about aspects of maternal self-efficacy according to the child's age, child's gender, and the mother's age. While, mothers of children with IDD, when compared to other mothers, had

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	and included background information about child's age, child's gender, mothers' age, type of disability (IDD, DS or autism), and child's respite facility for an afternoon. Arabic version of the caregiver self-efficacy scale of Kandari was used to assess mothers' perceptions about their ability to care for their child with DD. It included five subscales: behavior management, school issues, advocacy, emotional support, and provider issues.	mothers were selected from a variety of special education settings. Of the participants, there were 56 male and 39 female children with DD in the age-range 6–15 (M = 10.13, SD = 2.83). The children with DD had been diagnosed as having IDD, DS, or autism at the time that they entered the special education settings.	negative beliefs of all aspects of maternal self-efficacy. Mothers of children who did not attend a respite facility for an afternoon had negative beliefs of all aspects of maternal self-efficacy except for the child's behavioural management; and all mothers' groups had negative beliefs about their ability to control their child's behavior and their own emotions.
Kediye et al, 2009. Canada	**Aims**: report an investigation of the stress factors related to raising a child with ASD in Somali-Canadian families and asks the question: what are the maternal experiences of Somali-Canadian mothers parenting a child with ASD? **Design**: qualitative. **Methods**: Focus group interviews of one to one-and-one-half hours in length were carried out. The mothers	10 Somali-Canadian mothers of children diagnosed with varying degrees of severity ASD.	Many of the stresses reported by the mothers included anxiety over lack of developmental gains in their children with ASD and the resulting issues over safety and future independence. Tensions with key professionals such as teachers and doctors

Study Reference and country	Aims, Study Design and Methods	Participants	Results
	were asked to narrate their experiences and beliefs regarding the stresses they face in parenting a child with ASD. Open-ended questions that invited the mothers to discuss any stresses they were experiencing were developed.		were also noted as causing considerable stress and was perceived to result from limited language skills on the mothers' part, and lack of knowledge of Somali culture on the part of the professionals. The absence of an extended family in Canada was also noted as causing undue hardship for these mothers.
Crabtree S, 2007. United Arab Emirates	**Aims**: discuss family caregiving of children with developmental disabilities, with a particular focus on mothers. **Design**: qualitative. **Methods**: Ethnographic approach was used in which parent participants were interviewed intensively. The data were then analysed commensurate with ethnographic methodology in which parental care was considered in terms of gender differentials, in addition to other factors.	15 families who were local residents selected from the families of children with developmental disabilities attending the Sharjah City for Humanitarian Services, a semi-government-run body. Most of these mothers were married and were usually living in nuclear households.	Although mothers carried the main burden of support, this is ameliorated by cultural interpretations of the role of motherhood as well as practical coping strategies. Discrimination towards disability as well as gender is evident although countered by maternal strategies of resistance.

Of those 37, five studies were conducted in non-Arab countries but with Arab populations (Baker, 2017; Dolev et al. 2016; Fox et al. 2017; Kediye et al. 2009; Sher-Censor et al. 2017). The total number of Arab participants included in these studies was 120. There were no collaborative studies conducted across the Arab countries. Fourteen studies were conducted in Jordan and the rest of the studies were conducted in Saudi Arabia, Kuwait, Qatar, Lebanon, UAE, Iraq, West Bank, Egypt and Oman. There were 4,074 participants included in research from this theme. Topics researched included: (a) quality of life (QoL) of caregivers of children with ASD, and (b) psychological impacts of parenting a child with ASD. Studies on QoL of caregivers of children with ASD were carried out in Jordan, Iraq, and Qatar (Dardas & Ahmad, 2014d; Kareem & Ali, 2014; Kheir et al. 2012b). Only one study (Rayan & Ahmad, 2016) examined the impact of an intervention programme on improving the QoL and positive reappraisal coping among parents of children with ASD. This study implemented a mindfulness-based intervention with parents of children with ASD for five weeks. Results showed that parents had significant improvements in measures of the psychological health domain of QoL, the social health domain of QoL, mindfulness, and positive stress reappraisal with medium to large effect sizes. Studies on coping strategies as mediators and moderators between stress and QoL among parents of children with ASD were carried out in Jordan by Dardas and Ahmad (2015a, 2015b). Dardas and Ahmad (2015a) found that ‘accepting responsibility’ mediated the relationship between stress and QoL, while ‘seeking social support’ and ‘escape avoidance’ were moderators. Dardas and Ahmad (2015b) investigated the possible mediation and moderation effects of coping in the relationship between fathers of children with autism’s parenting stress and QoL. None of the investigated coping strategies were found to mediate or moderate the stress-QoL relationship among the participating fathers. Dardas and Ahmad (2014b) examined six predictors of QoL for parents of children with ASD: Parental Distress, Parent–Child Dysfunction Interaction, Difficult Child Characteristics, household income, and the child with ASD's age and number of siblings. Only parental distress emerged as a significant predictor of both mothers' and fathers' QoL, whereas difficult child characteristics, household income, and number of siblings were found to predict mothers' QoL.

There were in total 12 studies on psychological impacts of parenting a child with ASD (Al-Farsi et al. 2013; Al-Khalaf, Dempsey, & Dally, 2014; Alqahtani, 2012; Crabtree S, 2007; Dababnah & Parish, 2013; Dardas & Ahmad, 2014c; Dardas L, 2014; El bahnasawy & Naglaa, 2011; Fido & Al Saad, 2013; Kediye et al. 2009; Rayan & Ahmad, 2017; Zaki & Moawad, 2016). Fido and Al Saad (2013) examined the prevalence of parental depression in families of children with autism and in control families. The Arab version of the Depression Inventory was used to assess the psychological status of 120 parents of children with autism and a matched control sample of 125 parents of intellectually able children. Results revealed that mothers of autistic children had a significantly higher levels of problems for all dimensions of depression (Fido & Al Saad, 2013). Al-Khalaf et al. (2014) implemented an education programme for mothers of preschool age children with ASD. Following the education programme, results showed that the mothers reported a statistically significant reduction in stress levels, an increase in coping skills, and an improvement in mother-child interaction.

There were two studies conducted in Lebanon and Egypt in which the well-being of mothers of children with ASD were examined. Zaki and Moawad (2016) assessed the influence of autism awareness on the psychological well-being of Egyptian mothers caring for their children (n= 60) with autism. Results concluded that about two thirds of the studied sample had poor awareness regarding autism and there was a highly statistical significant relationship between awareness, stress and psychological well-being among mothers of children with autism. In Lebanon, Obeid and Daou (2015) examined and compared the effects of coping styles, social support, and their child's behavioural symptoms on the well-being of 65 mothers of children with ASD and 98 mothers of typically developing children. Results showed that disengagement and distraction coping predicted poor well-being, whereas cognitive reframing showed a correlation with better well-being levels. There was a significant correlation between the child's behavioural problems and maternal well-being. Mothers of children with ASD differed in terms of coping styles used and showed lower levels of perceived social support. Well-being was significantly better for mothers of typically developing children.

Social and Communication Behaviour of Arab Individuals with ASD

There were few studies that explored the social and communication behaviour of Arab individuals with ASD (n= 10, 14%) (Table 2.3).

Table 2. 3 Social and communication behaviour of Arab individuals with ASD

Study Reference and country	Aims, study design and methods	Participants	Results
Meiri et al, 2017. Israel	**Aims**: establish a hospital-university-based database of autism which incorporates prospective and retrospective data from a large and ethnically diverse population. **Design**: cohort. **Methods**: clinical assessment that includes a comprehensive intake interview regarding the clinical and socio demographic background of the diagnosed child, assessment with the Autism Diagnostic Observation Scale-2 test, and a cognitive evaluation using either the Bayley Scales of Infant and Toddler Development-third edition or the Wechsler Pre-school and Primary Scale of Intelligence	296 children [218 Jewish, 76 Bedouins, and 2 of mixed origin (Bedouin father and Jewish mother)] who are referred to the Child Development Institute or to the Preschool Psychiatric Unit with a suspicion of autism.	Results revealed that autism diagnosis was confirmed in 188 children (a male-to-female ratio of 4.5). Differences across the two ethnic groups were apparent in the rate of positive autism diagnoses, which was significantly higher among Jewish children than among Bedouin children (68.3 vs. 51.3%; $p = 0.0077$). In addition, average maternal age at birth of Jewish mothers was 5 years older than that of Bedouin mothers (31.25 vs. 26.02; $p<0.0001$). Bedouin children exhibited significantly lower cognitive test scores compared to Jewish children ($p = 0.013$), despite no significant differences in the levels of autism severity and

Study Reference and country	Aims, study design and methods	Participants	Results
			developmental milestones as reported by the parents between the two ethnic groups.
Fteiha M, 2016. United Arab Emirates	**Aims**: assess the effects of using assistive technology in improving the language skills with a sample of children having autism. **Design**: controlled clinical trial. **Methods**: Children Language Skills Scale was designed to measure the language skills of children with autism and included 64 vocabularies distributed on 4 aspects: matching, recipient language, verbal imitation, and expressive language. An educational program was developed based on the tactics of the Applied Behaviour Analysis. The scale was administered as pre-, post-, and follow-up.	12 children with autism (mean age=8 years) randomly assigned to either experimental groups or a control group (n=4 per group).	Statistically significant differences ($\alpha \geq 0.05$) between the average grade level of children with autism in the two experimental groups. The children in the two experimental groups made greater gains in language scores from pre- to post-test than those in the control group.
Alshurman & Alsreaa, 2015. Saudi Arabia	**Aims**: identify the efficiency of peer teaching of developing non – verbal communication to children ASD. **Design**: case-control. **Methods**:- Peer teaching sessions conducted by	10 children (5 experimental and 5 control) with ASD who aged between (8-12) Years and diagnosed according to basics and criteria	Statistically significant differences at (<0.05) Level in experimental group due to peer teaching, of developing non-verbal communication, efficiency

Study Reference and country	Aims, study design and methods	Participants	Results
	normal peers, through scheduling non formal interaction periods between children with autism and normal's, with high social skills and master non– verbal communication skills like shared attention skills visual communications imitation, listening and understanding, pointing to what is needed, understanding facial expressions and their indicative voice tones.	adopted at Al – Taif qualification centre at 2013.	to children with ASD, however these differences were not found between experimental and control groups on the scale at (2) month follow-up experiment, indicating the existence of program effect after two months of training.
Alzyoudi et al, 2015. United Arab Emirates	**Aims**: evaluate the impact of video modelling on an intervention designed to improve the social skills of children with autism. **Design**: single-subject study. **Methods**: Each child was asked to watch a videotape which presented two individuals interacting in a role-play setting. One person portrayed a therapist giving cues, while the second portrayed a child acting appropriately and demonstrating correct social behaviours. The boys were then asked to complete a social task and their performance was compared against baseline assessment measures. An A–B baseline design	5 children (boys 5-7 years old) with autism was selected from a centre-based programme that provides behavioural interventions for children with autism.	Results revealed that video modelling was an effective procedure for improving and promoting social skills for all five participating children. All the five children reached the mastery criterion for the acquisition of the target skills/behaviours.

Study Reference and country	Aims, study design and methods	Participants	Results
	across participants and settings was used to evaluate the impact of video modelling on exhibited social skills.		
Mashat et al, 2015. Saudi Arabia, Kuwait, & the United Arab Emirates	**Aims**: focused on the use of Facebook by Arab adults with ASD and the role of photos on their communication and interactions; the help of family and friends for preventing online vulnerability issues is taken into consideration. Further, focused on the cultural aspects that could have an impact on the use of social networks by adult Arabs with ASD. **Design**: cross sectional. **Methods**: Online survey was to be completed by the caregiver of the person with ASD in order to obtain permission from the family to contact the person with ASD. The first step is to ask the caregivers to create an account. The next step is to request each participant to implement a number of photo-related tasks with the help of the caregiver and to observe the participants' use of Facebook for a period of three weeks. An example of a	7 (all male) adults with ASD were eligible to be included in the study.	Results were not available

Study Reference and country	Aims, study design and methods	Participants	Results
	photo-related task is asking the caregiver to post a family photo on the participant’s wall or tag the participant in a photo. The impact of A Framework for Autistic Arabs' Social Communication and Interaction Technology will be explored during the observational phase and until the end of the study.		
Walker-Dalhouse & Dalhouse, 2015. United States	**Aims**: examine the school and home experiences of a Sudanese student, in an attempt to help teachers use culturally responsive teaching practices that promote the literacy development of Sudanese children with autism and to understand the challenges, needs, and expectations of Sudanese refugee parents who have children with autism. **Design**: case study. **Methods**: Observations and assessment was conducted to gather information about the Sudanese refugee boy. Unstructured interviews were conducted with his parents (asked about their experiences parenting a child with autism) and	one 6-year-old boy with high-functioning autism. The boy and his family live in the upper Midwestern part of the United States and the boy attended a community-based reading clinic at his family’s church for two times a week.	The boy continues to display an enthusiasm for reading and he is now reading above grade level. positive changes in the boy's interactions with other children at the clinic. His parents have reported similar progress at school. However, they continue to be challenged by obstacles in working with school personnel and have become more knowledgeable about advocating for their child in school settings.

Study Reference and country	Aims, study design and methods	Participants	Results
	with his uncle (focused on the boy's interactions with other Sudanese children and cultural expectations for behavior and his assessment of the boy's progress in school, home, and community setting).		
Perepa, 2014. United Kingdom	**Aims**: investigate the cultural influence on the understanding of what constitutes appropriate social behaviour by parents of children with ASD, belonging to four different ethnic backgrounds (White British, Somali, West African and South Asian) living in the United Kingdom. **Design**: qualitative. **Methods**: - Semi-structured interview was used to gather information about how parents define social behaviour, and whether there are differences in understanding on the basis of ethnicity. Parents were requested to rate six behaviours (using eye contact to communicate with adults and peers, using a range of facial expressions to express emotions, using gestures, interacting with adults and people in authority –	63 parents who have children with ASD belonging to four different ethnic communities (29 White British, 6 Somali, 16 West African and 12 South Asian) and living in the UK.	The importance that the parents give to various social skills varied on the basis of their cultural background and the gender of the parent. However, there were similarities in the importance attributed to particular behaviours, the Afro-Caribbean and Somali parents considered giving eye contact as the most important skill. The South Asian and White British parents considered following rules and respecting personal space the most important ones. Across all cultural groups, more fathers than mothers

Study Reference and country	Aims, study design and methods	Participants	Results
	initiating conversations, requesting and commenting respecting personal space; and following social rules, cues and boundaries for different situations). An open question was requested parents to add two more behaviours that they consider as important, which were not covered in the list.		considered using a range of facial expressions to be a difficult skill to teach.
Abd El-haliem et al, 2013. Egypt	**Aims**: investigate the eating habits for children with autism. **Design**: cross sectional. **Methods**: An interview questionnaire was used and included four main parts: one, includes items related to children's and parents' sociodemographic characteristics. Two, includes items related to history of disease. Three, includes items related to child eating habits. Four, includes items related to nutritional assessment.	112 autistic children distributed as the following: Al Sama centre (5 children), Al Saad centre (10 children), Awladna centre (10 children), Assiut rehabilitation centre (18 children), Female Association (18 children), Kayan Association (18 children), General Conversational Unit at Assiut University Hospital (20 children) and Seedy Galal students' Health Assurance clinic (13 children).	The majority of the studied sample had good appetite for specific food and all children favourite carbohydrate; therefore (60.7%) of them did not receive balanced diet. Also; nearly half of children (46.4%) had good eating during watching TV. The majority of children received medication that affect their appetite. 42.0% of the studied children were overweight.

Study Reference and country	Aims, study design and methods	Participants	Results
Huwaidi & Daghustan 2013. Saudi Arabia	**Aims**: identify the common sexual behaviours of the adolescents with autism from the perspective of both parents and teachers, taking into consideration the adolescent's functional level which impacts on sexual behavior. **Design**: cross sectional. **Methods**: Sexual Behavior Scale was developed to recognize whether the adolescent displayed any sexual behavior also collected basic demographic variables, including age, gender and date of birth. Social-Sexual Skills Scale was developed to recognize whether the adolescent knows and practices the proper social-sexual skills. A Screening Questionnaire for Asperger Syndrome and Other High Functioning ASD was translated by the researchers and used to show the level of functioning of adolescents with autism.	61 male adolescents aged 12 to 21 were recruited from private centres specializing in autism in three cities. After applying the exclusion criteria, 32 adolescents were taken from the main sample (15 have high functioning Autism, and 17 would have low functioning autism).	Both parents and teachers reported inappropriate sexual behavior expressed by the adolescents with autism. Significant correlations between both the social-sexual skills and reported sexual behaviours in all subtests and total scores. The high functioning adolescents with autism displayed significantly less inappropriate sexual behavior and significantly more social-sexual skills when compared to adolescents with low functioning autism.
Al-Shammar et al, 2010. Kuwait	**Aims**: develop an intervention strategy (LISTEN) that could be used to improve the inappropriate social behaviours of a student with autism (leaving his desk and stand very close to the	one male autistic student whose age was 21-year old in the last grade-year in the Autism School-KMOE	Implementation of the LISTEN strategy modified the targeted inappropriate social behavior of the participating autistic student.

Study Reference and country	Aims, study design and methods	Participants	Results
	visitor and remain uncommunicative) and gauge its effectiveness. **Design**: case study. **Methods**: LISTEN strategy (L for learn, I for interact, S for study, T for training, E for emulate, and N for normalize) was developed to help the autistic student reduce his inappropriate social behaviours in the classroom. Classroom activities were used.	that specializes specifically in educating students with autism.	Observational data showed that repeated modelling by the teacher was required during the first two steps of the LISTEN strategy before understanding of the strategy by the student was verified.

Of those 10, three studies were conducted in non-Arab countries but with Arab populations (Meiri et al. 2017; Perepa, 2014; Walker-Dalhouse & Dalhouse, 2015). The total number of Arab participants included in these studies was 44. There was one collaborative study conducted across Arab countries. Arab countries that contribute to this area of research were: Kuwait, UAE, Egypt, and Saudi Arabia. The total number of participants for studies in this area of research was 539. Most of the studies investigated the impact of intervention strategies on improving social and communicational skills of Arab children with ASD (Al Shammari, Daniel, Faulkner, & Yawkey, 2010; Alshurman & Alsreaa, 2015; Al zyoudi et al. 2015; Fteiha, 2016). For instance, Fteiha (2016) examined the effects of assistive technology on improving communication skills of children with autism (n=12) who were randomly assigned to either experimental groups or a control group (n= 4 per group). A language skills scale was administered to them as a pre- post- and follow-up test. Results revealed that there were statistically significant differences between the average grade level of children with autism in the two experimental groups. The children in the two experimental groups gained more language from pre- to post-test than those in the control group.

In addition, a study was conducted in Saudi Arabia to identify the common sexual behaviours of 32 male autistic adolescents 15 of whom were described as having “high functioning” autism, and 17 “low functioning” autism from the perspective of both parents and teachers, taking into consideration the adolescent’s functional level (which may impacts on sexual behaviour). Both parents and teachers reported inappropriate sexual behaviour expressed by the autistic adolescents. There were also significant correlations between both the social-sexual skills and reported sexual behaviours in all sub-tests and total scores. The high functioning adolescents with autism displayed significantly less inappropriate sexual behaviour and significantly more social-sexual skills when compared to adolescents with low functioning autism (Huwaidi & Daghustani, 2013). Interestingly, Abd El-haliem, Sharkawy, Mobarak, and Mohamed (2013) conducted a study to investigate the eating habits of (112) children with autism in Egypt. Results showed that children with autism had a less varied diet feeding behaviour and limited interests and difficulty in accepting change and types of foods that affected their weight.

Quality Appraisal Results

Ratings of the methodological quality of the qualitative studies are provided in Table 2.4. Six of the seven qualitative studies were rated as valuable research (Al-Dababneh, Al-Zboon, & Baibers, 2017; Alqahtani, 2012; Dababnah & Parish, 2013; Fox et al. 2017; Kediye et al. 2009; Perepa, 2014). The main areas of weakness for the qualitative studies were in providing enough information of how participants were selected, how ethical issues had been taken into consideration, whether the relationship between researcher and participants had been adequately considered (e.g., if the researcher critically examined their own role and considered potential bias during data collection), and how the process of data analysis had been conducted in terms of providing an in-depth description of it. The main strengths were in providing a clear statement of the aims of the research, selecting an appropriate methodology for addressing the research aims, and providing a clear statement of findings. One qualitative study (Crabtree S, 2007) was rated as not valuable research because of a lack of clear reporting of data analysis, ethical issues, and findings.

Table 2. 4 Quality assessment of methodology for included studies using a qualitative design: CASP The Critical Appraisal Skills Program (2014)

		References						
	CASP Questions	Dababnah& Parish, 2013	Perepa, 2014	Crabtree S, 2016	Alqahtani, 2012	Kediye et al, 2009	Al Dababneh et al, 2017	Fox et al, 2017
1	Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3	Was the research design appropriate to address the aims of the research?	No	Yes	Yes	Yes	Yes	Yes	Yes
4	Was the recruitment strategy appropriate to the aims of the research?	No	Yes	Yes	Yes	Yes	Yes	Yes
5	Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes

Table 2.5 presents the quality assessment results for the only Single Case Experimental Design study included in the review (Al zyoudi et al. 2015). The study met the applicable quality indicators, with exception of the indicator of external validity.

Table 2. 5 Quality assessment of methodology for Al-Zyoudi et al (2015)'s Single-Case Experimental Design study: The Quality Indicators tool developed by Horner et al. (2005)

	Quality Indicators questions	
1	Description of Participants and Setting • Participants are described with sufficient detail to allow others to select individuals with similar characteristic; (e.g., age, gender, disability, diagnosis). • The process for selecting participants is described with replicable precision. • Critical features of the physical setting are described with sufficient precision to allow replication	Yes
2	Dependent Variable • Dependent variables are described with operational precision. • Each dependent variable is measured with a procedure that generates a quantifiable index. • Measurement of the dependent variable is valid and described with replicable precision. • Dependent variables are measured repeatedly over time. • Data are collected on the reliability or inter observer agreement associated with each dependent variable, and lOA levels meet minimal standards {e.g., lQA = 80%; Kappa = 60%).	Yes
3	Independent Variable • Independent variable is described with replicable precision. • Independent variable is systematically manipulated and under the control of the experimenter. • Overt measurement of the fidelity of implementation for the independent variable is highly desirable	Yes
4	Baseline • The majority of single-subject research studies will include a baseline phase that provides repealed measurement of a dependent variable and establishes a pattern of responding that can be used to predict the pattern of future performance, if introduction or manipulation of the	Yes

	Quality Indicators questions	
	independent variable did not occur. • Baseline conditions are described with replicable precision.	
5	Experimental Control/internal Validity • The design provides at least three demonstrations of experimental effect at three different points in time. • The design controls for common threats to internal validity (e.g., permits elimination of rival hypotheses). • The results document a pattern that demonstrates experimental control.	Yes
6	External Validity • Experimental effects are replicated across participants, settings, or materials to establish external validity.	No
7	Social Validity • The dependent variable is socially important. • The magnitude of change in the dependent variable resulting from the intervention is socially important. • Implementation of the independent variable is practical and cost effective. • Social validity is enhanced by implementation of the independent variable over extended time periods, by typical intervention agents, in typical physical and social contexts.	Yes

Note. Yes the study meets the criterion, No the study does not meet the criterion

The quality assessment results for quantitative studies (n= 59) (see Table 2.6) revealed that two studies were rated as moderate in quality, while the remaining were rated weak. The main areas of weakness were selection bias, data collection methods, and withdrawals and dropouts. Selection bias included a lack of clear reporting of whether the individuals selected to participate in the study are likely to be representative of the target population and what percentage of selected individuals agreed to participate. In addition, there were a lack of clear reporting of validity and reliability for data collection methods that were used. Numbers and/or reasons for withdrawals and dropouts were not reported. Further, there was no indication whether confounders (variables that are associated with the intervention or exposure and causally related to the outcome of interest) were controlled in the design (by stratification or matching) or in the analysis. Data on intervention integrity was not provided in terms of the number of participants receiving the intervention (consider both frequency and intensity) and describing a method of measuring if the intervention was provided to all participants the same way.

Table 2. 6 Quality assessment of methodology for included studies using a quantitative design: EPHPP quality assessment tool for quantitative studies (Effective Public Health Practice Project (2007)

References		**Global Ratings**	**References**		**Global Ratings**
1	Al-Eithan et al, 2010	Weak	35	Seif Eldin et al, 2008	Weak
2	Hamadé et al, 2013	Weak	36	Akoury-Dirani et al, 2013	Weak
3	Al-Farsi et al, 2011	Weak	37	Al-Farsi et al, 2013	Weak
4	Hussein et al, 2011	Weak	38	Dardas & Ahmad, 2013	Weak
5	Amr et al, 2012	Weak	39	Fteiha M, 2016	Weak
6	Kheir et al, 2012	Weak	40	Rayan & Ahmad, 2016	Weak
7	Dirani & Salamoun, 2014	Weak	41	Dardas & Ahmad, 2014	Weak
8	Almansour et al, 2013	Weak	42	Zaki & Moawad, 2016	Weak
9	Raz et al, 2015	Weak	43	Al-Zahrani A, 2013	Weak
10	Al-Ansari & Ahmed, 2013	Moderate	44	Rayan & Ahmad, 2017	Weak
11	Mohammed, 2016	Weak	45	Fido & Al Saad, 2013	Weak
12	Al-Kandari & Al-Qashan, 2010	Weak	46	Dardas L, 2014	Weak
13	Dardas & Ahmad, 2014	Weak	47	Abd El-haliem et al, 2013	Weak
14	Al Jabery et al, 2014	Weak	48	Ahmad & Dardas, 2015	Weak
15	Abu-Hamour & Muhaidat, 2014	Weak	49	Taha et al, 2012	Weak
16	Estrem & Zhang, 2010	Weak	50	Mashat et al, 2015	Weak
17	Barnevik-Olsson et al, 2008	Weak	51	Dardas &Ahmad, 2014	Weak
18	Chaaya et al, 2016	Weak	52	Elbahnasawy & Girgis, 2011	Weak
19	Zeglam & Maound, 2012	Weak	53	Esler1et al, 2017.	Weak
20	Eapen et al, 2007	Weak	54	Al-Kandari, 2017.	Weak

References		Global Ratings	References		Global Ratings
21	Dardas & Ahmad, 2014	Weak	55	Alnemary et al, 2017	Weak
22	Dardas & Ahmad, 2014	Weak	56	Eid et al, 2017	Weak
23	Kareem & Ali, 2014	Weak	57	Hemdi & Daley, 2017.	moderate
24	Kheir et al, 2012	Weak	58	Sher-Censor et al, 2017.	Weak
25	Dolev et al, 2016	Weak	59	Meiri et al, 2017.	Weak
26	Mohamed et al, 2016	Weak			
27	Amr et al, 2011	Weak			
28	Huwaidi & Daghustan 2013	Weak			
29	Amr et al, 2012	Weak			
30	AlAyadh et al, 2015	Moderate			
31	Al-Khalaf et al, 2014	Weak			
32	Obeid & Daou, 2015	Weak			
33	Alshurman & Alsreaa, 2015	Weak			
34	Raddad et al, 2011	Weak			

Discussion

The current review has provided an overview of the current state of the field of social, educational, and psychological research focused on individuals with ASD and/or their family members, in Arab countries and cultures. Seventy studies met the inclusion criteria for the review. The results revealed that there is growing interest in recent years in social, educational, and psychological research focused on individuals with ASD and/or their family members in some Arab countries, especially in Jordan, Saudi Arabia, and Lebanon. The lack of literature from other parts of the Arab world, for instance the Maghreb (consisting of the countries Algeria, Morocco, Tunisia, Libya and Mauritania) may be due to the fact that there may be published research on ASD in other languages than English and Arabic. For instance, Algeria, Morocco, and Tunisia were an important part of the French Empire in the nineteenth and early twentieth centuries and despite gaining independence, the French language continues to be an important language in many areas of life (Aitsiselmi & Marley, 2008). Accordingly, there might be some published literature on ASD in Arab countries in the French language.

The most commonly applied methodologies were quantitative (59), with four of these studies only being Randomized Controlled Trials (RCTs) or other controlled comparisons of interventions. There were also seven qualitative, one single case experimental design study, and three case studies. Most of the studies used cross-sectional designs. Questionnaires were the predominant data collection method. The use of cross-sectional designs can be useful for estimating the prevalence of a behaviour or condition in a population (Sedgwick, 2014), and for exploring associations between potential risk factors and outcomes of interest. However, these designs are limited by the fact that they are conducted at one timepoint and thus give no indication of the sequence of events. Therefore, it is impossible to infer causality (Levin, 2006). In addition, most of the included studies that used cross-sectional designs gave minimal consideration to possible confounding variables, and there was rarely an indication of the validity and reliability of measures used. Studies evaluating interventions also had a number of limitations leading to their low-quality ratings. Thus, using the current evidence base to inform future ASD research and policies in the Arab world should be done with caution. Parents/ caregivers of individuals with ASD were the most targeted populations in the included studies. A few studies were conducted in non-Arab countries (e.g. United States, United Kingdom, Israel, Canada, and Sweden) but with Arab populations. Most of these studies focused on experiences and outcomes for caregivers of individuals with ASD.

There has been research in three broad domains: (1) the prevalence of ASD and diagnosis issues, (2) the experiences and outcomes for Arab caregivers of individuals with ASD, and (3) social and communication behaviour of Arab individuals with ASD. One third of the reviewed studies explored prevalence of ASD and diagnosis issues. Samples from hospital, specialist units, and preschools were commonly used. The range in prevalence in the included studies was 0.014% - 4.7%. However, given that the research was generally rated as low quality, it is not appropriate to draw any strong conclusions about the likely prevalence rate for ASD in Arab countries. In addition, there were few screening and diagnostic tools that had been validated for the Arab context. The experiences and outcomes for Arab caregivers of individuals with ASD were the majority of the reviewed studies (53%). There was a focus on psychological impacts of parenting a child with ASD which reflects a significant impact on quality of life that Arab caregivers are increasingly experiencing. Therefore, there is growing interest in understanding better care and management practices to avoid this burden.

However, studies on quality of life of caregivers of individuals with ASD arose from only three Arab countries, that is, Jordan, Iraq, and Qatar. The least researched domain was the social and communication behaviour of Arab individuals with ASD (14%). The focus of these studies was on the impact of intervention strategies on improving social and communicational skills of Arab children with ASD

Our review indicated that there were significant gaps in research evidence base. For instance, research on interventions, particularly educational interventions, was scarce. In addition, there were few data on ASD services in terms of their organisation, effectiveness, or consumer perspectives. Only one study (Al Jabery, Arabiat, Al Khamra, Betawi, & Abdel Jabbar, 2014) investigated the perceptions and experiences of parents of children with ASD regarding provided services in Jordan.

Amongst the intervention studies published, there were very few RCTs and only one study used a Single-Subject Experimental design. However, RCTs and Single-Subject Experimental designs are commonly used to define the effectiveness of behavioural and educational interventions for autism (Dounavi & Dillenburger, 2013). The very few RCTs that have been published had very limited sample sizes and a lack of evaluation of long-term impact. Current evidence is insufficient to provide the required information to plan appropriately for effective intervention strategies for individuals with ASD in Arab countries.

Further research is needed to explore the most effective and efficient strategies for improving intervention and service delivery to Arab individuals with ASD and their family members in the context of a given country, culture, and governmental system. Arab countries still vary enormously in terms of their political, ethnic, economic, social, and religious characteristics (Al- khateeb et al. 2016; Hussein & Taha, 2013) and so contextually relevant research is needed. Future research should be conducted to address areas including developing or adapting screening and diagnostic tools as there were few screening and diagnostic tools that had been validated for the Arab context. Overall, the quality of the vast majority of included research studies was weak. Thus, a priority is likely research training and building the research infrastructure for ASD and related research in Arab countries. Moreover, research on adults with ASD is a high priority as there were few studies that focused on adults with ASD. In addition, none of the included studies from the searches mentioned non-Arab participants living in Arab countries. Therefore, future research should also consider non-Arab populations living in Arab countries.

This review has certain limitations that need to be taken into consideration. The most apparent limitation is language bias as all included studies were published in English (although the inclusion criteria included the Arabic language). Consequently, this review may have missed some articles published in the Arabic language. However, it is very difficult to access Arab literature because Arab electronic databases are still lacking (Al- Khateeb & Al- Khateeb, 2014). Additional elements of the search strategy identified a significant number of studies not previously identified in searches. However, according to CRD (2009) conducting forwards and backwards citation searching (checking reference lists of included studies; checking citations of included studies, and checking reference lists of other reviews on the topic) aim to identify publications that have not been included and indexed by electronic databases or from journals that are not indexed by electronic databases. In addition, CRD (2009) indicated that such additional searches can compensate for inaccurate database indexing that can result in even the most carefully constructed strategy failing to identify relevant studies. There were also not enough studies with similar research questions to enable metaanalytic summaries of the research evidence. However, this is a priority in future when sufficient evidence has been amassed.

Chapter 3: Support Needs of Arab Families of Children with Autism Spectrum Disorder Living in the United Kingdom

Abstract

Raising a child with Autism Spectrum Disorder (ASD) has been linked to a range of negative outcomes for families, but less is known about the putative impact upon Arab families living in the United Kingdom (UK). In this exploratory study, we investigated support needs, psychological distress, and parental relationships of 100 parents of children with ASD from Arab families living in the UK. Results revealed that the most frequently identified support needs were information, community services, and explaining to others. Parents reported high levels of psychological distress, but also a high level of parental relationship satisfaction with their spouse and few parental disagreements over issues related to their child with ASD. Regression analyses showed that increased child behaviour problems predicted more total family needs. Higher levels of child prosocial behaviour, better health status of parents, and a larger number of children in the family were associated with lower levels of parental psychological distress. A longer time living in the UK was associated with more parental disagreement over issues related to the child with ASD.

Introduction

Autism Spectrum Disorder (ASD) is a developmental disability that affects approximately 1 in 59 children (Centre for Disease Control and Prevention, 2018) and is characterised by repetitive behaviour or interests, and impairments in social interaction and communication (American Psychiatric Association, 2013). ASD is a lifelong condition that affects not only the development of the individual but also the family environment (Gau et al., 2012; Harper, Dyches, Harper, Roper, & South, 2013; Johnson, Frenn, Feetham, & Simpson, 2011). Raising a child with ASD can be a profoundly challenging experience for many parents, and may conceivably have an effect on their personal health (Cohrs & Leslie, 2017). The challenges in obtaining a diagnosis, locating appropriate treatment and educational programmes, and paying for ASD services, given the nature of these children's needs, accessible resources, and complicated financial plans, can lead to considerable stress for parents (Cohrs & Leslie, 2017; Whitman, 2004). In addition, parents of children with ASD have to cope with challenging associated behaviours, such as sleeping and eating problems, and behavioural and emotional problems (Humphreys et al., 2014; Johnson, Giannotti, & Cortesi, 2009; Martins, Young, & Robson, 2008).

The impact of ASD is multidimensional as it affects the family financially, socially, and in terms of employment; but also raising a child with ASD may affect the physical and mental health of parents (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Parents of children with ASD report having elevated parenting stress (Estes et al., 2013; Hayes & Watson, 2013; Lai, Goh, & Sung, 2015) and psychological distress including depression and anxiety symptoms (Abbeduto et al., 2004; Al- Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016;

Hodge, Hoffman, & Sweeney, 2011; Keenan, Newman, Gray, & Rinehart , 2016) compared to parents of children who do not have ASD. There is also evidence that parenting stress persists throughout the course of a child's early development (Herring et al., 2006; Zaidman-Zait et al., 2014) and continues into adolescence and adulthood (Smith et al., 2010).

Raising a child with ASD may change the everyday life and long-term outlook of couples. Due to the additional practical, emotional and financial challenges of raising a child with ASD, parents may have less time to spend with one another, struggle to manage their partner's reaction to having a child with a disability, and encounter difficulties balancing their role as a partner and a parent (Brobst, Clopton, & Hendrick, 2009). As a result, parents of children with ASD have been found to report lower levels of relationship satisfaction when compared with parents who do not have children with disabilities (Brobst et al., 2009; Hartley, Barker, Baker, Seltzer, & Greenberg, 2012; Higgins, Bailey, & Pearce, 2005; Gau et al., 2012; Santamaria, Cuzzocrea, Gugliandolo, & Larcan, 2012; Sim, Cordier, Vaz, & Falkmer, 2016) and parents who have children with intellectual disability (Kwok, Leung, & Wong, 2014) or Down syndrome (Rodrigue, Morgan, & Geffken, 1990; Santamaria et al., 2012). In addition, Hartley et al. (2010) reported that marital problems persist over time in families raising children with ASD.

Social support may help to alleviate the negative outcomes associated with raising a child with ASD (Bromley, Hare, Davison, & Emerson, 2004; Hassall, Rose, & McDonald, 2005). Research on parents of children with ASD has found that social support is linked to lower levels of psychological distress (Bromley et al., 2004), negative mood (Pottie, Cohen, & Ingram, 2009), depressive symptoms (Ekas, Lickenbrock, & Whitman, 2010), fewer marital problems (Dunn et al., 2001), as well as higher levels of parental relation satisfaction (Brobst et al., 2009; Ekas, Timmons, Pruitt, Ghilain, & Alessandri, 2015). Dunst, Trivette and Hamby (1994) defined social support as the assistance an individual receives from others. Support can be emotional, psychological, physical, informational, instrumental and material help that affects the receiver's behaviour either directly or indirectly (Dunst et al., 1994). Support can come from formal or informal sources (Dunst & Trivette, 1990). Formal support is provided by an agency or organisation in the form of social, psychological, physical, or financial support. Informal support is the assistance that provided by someone in the individual's network that involves family, friends, neighbours and parents of other children with disabilities (Boyed, 2002; Bristol & Schopler 1983). Albanese, Miguel and Koegel (1996) stressed that professionals should start with an assessment of the needs and wishes of the family to initiate appropriate social support. Dunst, Trivette, and Jenkins (1988, p. 13) define need as "an individual's judgment of the discrepancy between actual states or conditions and what is normative, desired, or valued from a help seeker's and not a help giver's perspective". Comprehensive assessment of family needs can enhance the formulation of meaningful interventions to address parents' particular concerns and desires (Baker, 1989; Plienis, Robbins, & Dunlap, 1988; Singer, Irvin, & Irvin, 1989).

Bailey and Simeonsson (1988) designed a measure, the Family Needs Survey (FNS), to assess the needs of 34 two-parent families participating in home-based intervention programmes for infants with a variety of disabilities (average age = 14 months). The survey consisted of 35 items categorised into six derived clusters: needs for information, e.g., 'I need more information about how to teach my child', needs for support, e.g., 'I need to have more friends that I can talk to', explaining to others, e.g., I need help in explaining my child's condition to other children', community services, e.g., 'I need help locating a dentist who will see my child', financial needs, e.g., 'I need more help in getting special equipment form my child's needs', and family functioning, e.g., 'our family needs help deciding on and doing recreational activities'. The FNS was used by Ellis et al. (2002) to assess the needs of 91 families of children with developmental disabilities (90% with a diagnosis of ASD) up to the age of 22 years. Results showed that parents' greatest reported needs were for information, support, and community services. Financial assistance was the lowest reported need. In addition, Ellis et al (2002) evaluated situational variables that predicted needs and found that parents of younger children with ASD report the greatest needs overall, while parents' age, education, income, number of siblings, and participation in support services did not predict self-reported needs. Fewer reported needs were identified by families who had a child enrolled in a residential setting. Recently, Hodgetts, Zwaigenbaum, and Nicholas (2015) assessed the needs of 143 families of children with ASD (2 - 18 years). The study found that the most commonly unmet needs were the need for information about services for the child both now and in the future; family support and respite care. Quality of professional support available was viewed positively. The child's age, mother's age and household income were significant predictors of more total needs. Having an older child or mother, lower income, and disruptive behaviours predicted more total unmet needs. Children's language or intellectual abilities did not predict needs.

Different ethnic and cultural groups can vary considerably in their beliefs about disability, the nature of family and community supports, ethnomedical practices, and the utilisation of professional services (Harry, 1992; Ingstad & Whyte, 1995). For example, in comparing Chinese and Malay Muslim mothers of children with intellectual disabilities, Ow, Tan, and Goh (2004) found that patterns of reported social support differed by culture. The Malay Muslim mothers did not have any sources of formal support, while approximately half of the Chinese mothers did. Ow et al. (2004) argued that religious and cultural beliefs, cognitive frameworks, and satisfaction with informal supports may influence formal support needs and service use by different populations. Language barriers may also impede the access to social support (Carter, Park, & Cragg, 2015; Lo, 2010). Bailey et al. (1999) argued that researchers have paid more attention to the variance of interethnic group than across families within a given ethnic group, particularly when the ethnic group is a minority with respect to the majority culture and language.

Findings from the systematic scoping review (Chapter 2) showed that research on support needs of Arab families of children with ASD is absent. Further, there were only six studies on parent psychological distress or mental health (Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaidan, 2013; Dardas, 2014; Fido & Al Saad, 2013; Obeid & Daou, 2015; Rayan & Ahmad, 2016; Zaki, El Nabawy, & Moawad, 2016) but no studies about parental relationships in families of children with ASD. Consequently, the rationale of this study was partly informed by the systematic scoping review. In addition, to our knowledge, no published studies have focused on the support needs of Arab families of children with ASD living in the UK. Therefore, the main aims of the current exploratory study were to: 1. Describe support needs, psychological distress and parental relationships of Arab families of children with ASD, living in the UK, and 2. To identify factors that predict these outcomes.

Methods

Participants

Participants were Arab primary caregivers (83 biological mothers and 17 biological fathers) of children with ASD. Ninety-three of the participants were married and the remainder were divorced, separated or widowed. Mothers and fathers were well-educated: 22 had school leaving qualifications, 51 with a college or university degree, 15 held Master's or Doctoral degrees, and only seven with no formal educational qualifications. Fifty of the parents were aged between 35 and 44 years old, 40 of them were between 25 and 34 years old, only one parent was under the age of 24, while nine of them were between the age of 45 and 54. Thirty-three parents were employed and the remainder were unemployed. As shown in Table 3.1, the participants were originally from 19 different Arab countries. The majority of them came from Iraq (12), Egypt (11) and Syria (11). They were all born in an Arab country other than the UK, and their time length in the UK ranged from one year to 38 years (M = 10.05, SD = 7.54).

Table 3. 1 Participants' Arab identity

Country	Number of participants	Country	Number of participants	Country	Number of participants
Egypt	11	Lebanon	3	Somalia	9
Sudan	5	Kuwait	2	Jordan	6
Morocco	6	Qatar	1	Palestine	6
Yemen	4	Algeria	6	Bahrain	2
Tunisia	5	Iraq	12	Oman	2
United Arab Emirates	2	Saudi Arabia	2		
Libya	5	Syria	11		

One family had three children under 18 years of age who were diagnosed with ASD, three families had two children with ASD, while the remainder reported that they had only one child with ASD. On average, families had three children (M = 3.08, SD =

1.21; range 1 - 7) and two adults above 18 years of age currently living in the family's home (M = 2.02, SD = .49; range 1 - 5). A family socioeconomic disadvantage variable was created including three indicators: the parent had no educational qualifications (scoring one), reporting of family financial hardship [rating of 'finding it quite difficult' or 'finding it very difficult' in response to 'how well would you say you and your husband/wife/partner are managing financially these days?'] (scoring one), and the household income below £600 per week (scoring one). These indicators were summed to obtain a disadvantage index. Only one family had no disadvantage indicators, 19 families had one, 70 families had two, and 10 families had three disadvantage indicators. The mean score for this disadvantage index was 1.89 (SD = .57).

The children with ASD were between the ages of 4 and 15 years of age (M= 10.02, SD = 35.297), and were predominantly male (78%). According to parental report, 99 of the children had received a diagnosis of autism, and one of Asperger Syndrome. Thirty-three families reported that it took more than one year from raising their initial concerns about their child to obtaining the ASD diagnosis, while other families reported that it took about one year (30 families), about six months (24 families), and about three months (13 families).

Measures

Participants completed an anonymous online or postal survey (see Appendix B, p. 305) that included: a demographic questionnaire designed for the present research to assess characteristics described above, and questionnaires measuring child behaviour problems, family needs and parental psychological distress.

Child measures.

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) was used to measure children's behavioural and emotional problems. This measure comprises 25 items assessing five domains: prosocial behavior domain, e.g., considerate of other people's feelings, and four problem behaviour domains including emotional problems, e.g., often complains of headaches, stomach-aches or sickness, conduct problems, e.g., often fights with other children, hyperactivity, e.g., constantly fidgeting or squirming, and peer relationship problems, e.g., rather solitary, tends to play alone. Respondents rated statements about their child as either not true, somewhat true, or certainly true. The SDQ total difficulties score was generated by summing emotional problems, conduct problems, hyperactivity and peer relationship problems as the measure of children's behavioural and emotional problems. A higher score is indicative of greater behavioural and emotional difficulties. The SDQ has demonstrated good levels of reliability and validity for use as a community screening tool for children and adolescents (Goodman, 2001). Research with children with ASD suggested that the SDQ maintains good psychometric properties when it is used in this population (Jones et al. 2014; Totsika et al. 2011, Iizuka et al. 2010). In the present sample, a Cronbach's alpha of .74 was obtained for the total difficulties score and .75 for the prosocial behaviour subscale.

The GO4KIDS Brief Adaptive scale was used as a measure of adaptive behaviour (Perry et al. 2014). This measure contains eight items that provide an assessment of a child's adaptive behaviour across four domains: support needs, communication, socialisation, and self-help skills. A new item 'How much does your child use alternative methods of communication to communicate? (e.g., signing, symbol systems, Picture Exchange Communication System) (If applicable)' was added to the measure. Each item is rated on a five-point scale, with higher scores indicating greater skill level and greater independence. An overall adaptive behaviour score was derived by summing the ratings on the nine items (cf. Perry et al. 2014). Satisfactory reliability and validity has been demonstrated with parents of children and youth with developmental disabilities (Perry et al. 2014). Cronbach's alpha for the total score in the current study was .81.

Parental measures.

Parents' psychological distress was measured using the Hospital Anxiety and Depression scale (HADS; Zigmond & Snaith, 1983). Although initially developed for residential psychiatric populations, the HADS has been used widely in community research. This measure comprises 14 items, with seven assessing depression, e.g., 'I feel as if I am slowed down', and seven assessing anxiety, 'e.g., 'I feel tense or wound up'. A dimensional approach was taken for the analyses in the present study with a total score for all 14 items being used. Previous research with parents of children with developmental disabilities has shown that the HADS maintains good reliability within these populations (Alnazly & Abojedi, 2019; Hastings & Brown, 2002; Hastings et al., 2005). For the current sample, Cronbach's alpha level for the total psychological distress total score was .82.

The Family Needs Survey (FNS; Bailey et al., 1992) was used to assess family needs. This survey consists of 35 items reflecting needs commonly expressed by parents of children with disabilities, e.g., 'how to handle my child's behavior'. The items organised into seven domains: information, e.g., 'how to teach my child', family and social support, e.g., 'talking with someone in my family about concerns', financial assistance, e.g., 'getting any special equipment my child needs', explaining to others, e.g., 'explaining my child's condition to his or her siblings', child care, e.g., 'locating babysitters for my child', professional support, e.g., 'meeting with a counsellor', and community services, e.g., 'locating a doctor who understands me and my child needs'. In the present study, parents rated on a 3-point scale: 1 indicated a response of 'no support needed', 2 indicated 'a little support needed' and 3 indicated 'a lot of support needed'. Previous research with parents of children with developmental disabilities has reported that the FNS maintains good reliability within these populations (Bailey et al., 1999; Ellis et al., 2002). Cronbach's alpha for FNS total score in the present study was .88.

Parental relationship satisfaction was measured using a scale that described degree of happiness with spouse or partner. Parents selected options from 1 – 7, where '1' represented a very unhappy relationship and '7' was a very happy relationship. This outcome was dichotomised into two categories: high relationship satisfaction and lower relationship satisfaction. After running descriptive statistics, we found that the majority of responses in the sample fell into '6 and 7' options, while there were a few responses which fell into '1- 5' options. Thus, scores of 6 or 7 were classified as high relationship satisfaction, while the remainder of scores were classified as lower relationship satisfaction. Parental disagreement over issues related to their child with ASD was rated on a 6-point scale from 'never' to 'more than once a day'.

Procedure

Translation process.

Three questionnaires (demographic questionnaire and the parent relationship items, the GO4KIDS Brief Adaptive scale, and the FNS) (see Appendix C, p. 322) were translated into Arabic in addition to participant information sheets (see Appendix D, p.

338) and consent forms (see Appendix E, p. 341). There were already Arabic versions of the SDQ and the HADS. Therefore, the survey was available for completion in English or Arabic, depending on respondents' preferences. We used the following translation procedures.

Step 1: Forward translation.

After obtaining the authors' permission to use the GO4KIDS Brief Adaptive scale and translate it into Arabic, the first researcher translated the demographic questionnaire, the GO4KIDS Brief Adaptive scale, and the FNS. Literal translation was avoided. Rather, the meaning of the statements as a whole unit was considered. Two additional bilingual individuals were also asked to translate the questionnaires into Arabic. A comparison was made between the first researcher's translation and the other two individuals' translation. An initial Arabic version was produced after a few alterations were made at this stage. Three bilingual individuals who are experienced in working with children with disabilities were then asked to check the appropriacy of the translation. The final Arabic versions were produced after obtaining a few comments and feedback from these bilingual individuals. A final Arabic version was approved in terms of the level of written standard Arabic by an expert in the Arabic language.

Step 2: Back translation.

The Arabic translation resulting from the end of the first step was given to another bilingual individual who has a PhD in psychology from the UK, and is experienced in translation. She was asked to back-translate the three new Arabic questionnaires into English.

Step 3: Comparison and revision.

The original English questionnaires and the back-translated English versions, which resulted from Step 2, were compared by an English speaker to check for mismatches. He noticed that some items in the back translation where the meaning might be too far from the original English. A small number of alterations in Arabic were made in the Arabic version to help convey closer to the original English versions.

Recruitment of Participants

Recruitment was initiated upon receiving approval from the University of Warwick Humanities and Social Sciences Research Ethics Committee (HSSREC, ref: 70/16-17) (see Appendix F, p. 342). Primary caregivers of children with ASD who are aged between 4 years and 15 years 11 months, from Arab families living in the UK, were eligible to participate in the study if they self-identified as originating from one of the following 22 Arab League states: Algeria, Somalia, Egypt, Libya, Sudan, Tunisia, Morocco, Mauritania, Djibouti, Bahrain, United Arab Emirates, Oman, Kuwait, Qatar, Saudi Arabia, Yemen, Jordan, Syria, Iraq, State of Palestine, Lebanon, and Comoros. Primary parental caregivers were not necessarily the child's mother but the adult who cared for the child with ASD for most of the time. Mothers may also have been biological, adoptive, or foster mothers.

A variety of different routes were used to contact Arab primary caregivers of children with ASD in the UK such as via autism and child disability charities, or special schools that provide services to children with autism, and online via Facebook, Twitter and WhatsApp groups, recruitment flyers in both English (see Appendix G, p. 343) and Arabic (see appendix H, p. 344), and presentations at meetings of parent groups. Recruitment information included a brief description of the study and links to access the survey in both English and Arabic. One month after sending a recruitment email (see

Appendix I, p. 345), a reminder letter (see Appendix J, p. 346) was emailed to all previous contacts. Another reminder letter was also emailed before closing the survey (see Appendix K, p. 347). Families received no payment or other benefit for cooperating with the study. Participants information sheets (see Appendix L, p. 348) and consent forms (see Appendix M, p. 353) were accompanied with both online and postal survey.

During the recruitment process, to enable responses of Somali families, Somali language versions of the information sheet (see Appendix N, p. 354) and consent forms were developed (see Appendix O, p. 359). Somali parents attending a support group were offered an option to complete the survey face-to-face. Nine parents participated in the survey by completing it face-to-face.

Data Analysis

Before the main statistical analyses were conducted, the main study variables (family needs and levels of parental psychological distress) were tested for the normality of their distributions using skewness and kurtosis tests. The values of skewness and kurtosis tests revealed that the variables approximated a normal distribution Data analysis proceeded in several steps. First, descriptive analysis was conducted to identify family needs, levels of parental psychological distress and parental relationship satisfaction, and parental disagreement (over issues related to the child with ASD). Second, the analyses used linear regression models. Three analyses, one predicting family needs, the second predicting psychological distress levels in parents, and the third predicting parental disagreement over issues related to the child with ASD. Child predictor variables included the total score of SDQ prosocial scale, total score of the GO4KIDDS Brief Adaptive scale, the total difficulties score of the

SDQ, child's age and gender; and parent predictor variables included current health status, employment status, length of time living in the UK, socioeconomic status [using the disadvantage index score], number of children in the family, and number of ASD children in the family. All these variables were entered into the model at once and the residuals were inspected. Third, logistic regression was conducted to examine child and parent predictor variables for relationship satisfaction. Logistic regression was fitted to this outcome because it was measured as a categorical variable (high vs lower parental relationship satisfaction – see above). There were no missing data, except that participants' responses of 'can't say' to the parent relationship measures were considered missing. Statistical analyses in the study were conducted using IBM SPSS Statistics 25^{VR}.

Results

Descriptive Analysis

The mean score for the overall level of reported family needs was 73.30 (SD = 11.27). Subscales or topic areas with the highest means included need for information (M = 2.73; SD = .421), community services (M = 2.62; SD = .608) and explaining to others (M = 2.07; SD = .576). The most commonly reported needs were the need for information about current available services as well as services that the child might receive in the future; information regarding how to teach and handle the child's behaviour; meeting and talking with other parents who have a child with ASD; locating a dentist for the child; and finding reading material about other families who have a child with ASD. The least frequently reported needs were meeting with an imam, priest, or rabbi; the need for help in deciding who will do household chores, child care and other family tasks; needs related to getting appropriate care for the child in a mosque, church or synagogue during religious services; the need for counselling or help in getting a job; and deciding on and doing family recreational activities.

On average, parents had a total score on the HADS of 17.65 (SD = 6.30). For the anxiety subscale the mean score was 9.14 (SD = 4.02) and for the depression subscale it was 8.51 (SD = 3.21). A cut-off score of 11 was used as an indication for presence of either depression or anxiety (participants scoring 11 and above). Using this cut-off, 27% of parents were identified as having depression and 37% were identified as having anxiety.

Sixty-two percent of the parents reported high relationship satisfaction with their spouse, while 23% reported lower relationship satisfaction. Descriptive statistics on parental disagreement over issues related to the child with ASD revealed that 44% of the parents reported no disagreement over issues related to the child, 17% reported disagreements 'less than once a week', once a week by 11%, several times a week by 6%, while disagreements once a week and more than once a week were reported by 1% and 4% respectively.

Regression Analyses

For total family needs the regression model explained 14% of the variance (Adjusted $R^2 = .141$). Only the total difficulties score of the SDQ made a significant contribution to the prediction of total family needs ($\beta = .326$), with more child behaviour problems associated with increased family needs. No other predictors were statistically significant.

For psychological distress levels, multiple regression analysis showed that total score of child's prosocial behaviour scale, health status of parents and number of children in family were significant predictors (β = -.423, -.259 and -.218) respectively, with a negative relationship to total psychological distress of parents (Table 3.2). No other predictors were statistically significant. The model explained 23% of the variance in total psychological distress (Adjusted $R^2 = .228$).

Table 3. 2 Results of linear regression analysis of family needs, psychological distress and parental disagreement

Predictor variables	Family needs			psychological distress			parental disagreement		
Child variables	B	β	p	B	β	p	B	β	p
Age	-.036	-.113	.350	-.011	-.095	.406	-.009	-.217	.088
Gender	.170	.006	.953	-.845	-.083	.412	-.347	-.108	.362
Prosocial total score	-.459	-.104	.441	-.698	-.423	.001	-.021	-.041	.778
GO4KIDS total score	-.320	-.176	.203	.043	.063	.632	.043	.193	.189
SDQ	.748	.326	.009	.086	.100	.390	-.021	-.041	.778
Parent variables									
Health status	-.896	-.036	.769	-2.421	-.259	.028	-.228	-.076	.583
Employment status	.759	.032	.782	.142	.016	.884	.030	.011	.932
Time length in UK	-.075	-.050	.651	.031	.056	.593	.056	.296	.013
Family disadvantage	1.830	.092	.416	-.425	-.057	.595	.161	.060	.610
Number of children in family	.828	.089	.418	-.758	-.218	.039	-.084	-.072	.538
Number of ASD children in family	-2.426	-.056	.586	1.179	.073	.456	.501	.098	.384

As shown in Table 3.2, time length in the UK was a significant predictor (β = .296), with a positive relationship to parental disagreement over issues related to the child with ASD. No other predictors were statistically significant. The model explains 20% of the variance in parental disagreement outcome (Adjusted R^2 = .202).

Logistic regression analysis revealed that the model as a whole explained between 14.5% (Cox and Snell R squared) and 21% (Nagelkerke R squared) of the variance in parental relationship satisfaction, and correctly classified 72.9% of cases. As shown in Table 3.3, only parents' employment status predicted parental relationship satisfaction. Employed parents were less likely to report a high relationship satisfaction with their spouse or partner by a factor of .189 (95% CI .046 and .777).

Table 3. 3 Results of logistic regression analysis predicting parental relationship satisfaction

Predictor variables	B	S.E.	Wald	df	p	Odds Ratio	95% C.I. for Odds Ratio	
Child variables							Lower	Upper
Age	.006	.009	.353	1	.552	1.006	.987	1.025
Gender	.29	.732	.157	1	.692	1.337	.318	5.617
Prosocial total score	.159	.147	1.173	1	.279	1.172	.879	1.562
GO4KIDS total score	-.018	.065	.079	1	.779	.982	.865	1.114
SDQ total score	-.066	.068	.941	1	.332	.936	.820	1.070
Parent variables								
Health status	1.306	.783	2.784	1	.095	3.692	.796	17.120
Employment status	-1.664	.72	5.335	1	.021	.189	.046	.777
Time length in UK	-.029	.038	.574	1	.449	.971	.901	1.047
Family disadvantage	.985	.619	2.536	1	.111	2.679	.797	9.009
Number of children in family	.114	.243	.221	1	.639	1.121	.696	1.805
Number of ASD children in family	-1.674	1.669	1.005	1	.316	.188	.007	4.945
Constant	1.033	2.555	.163	1	.686	2.809		

Discussion

Raising a child with an ASD inevitably generates needs for families across many domains of life. The pattern of needs reported by the parents in the current study is consistent with that found in previous research (e.g., Bailey et al., 1999; Ellis et al., 2002; Hodgetts et al., 2015; Ma, 2016; Sexton, Burrel, & Thompson, 1992). For example, at the domain level, information needs have consistently been shown to be higher than other domains of needs. In addition, at the item level, needs related particularly to the child's condition, for example need for information about services for the child both now and in the future, information on how to teach and handle the child's behaviour, meeting with other parents who have a child with ASD, locating a dentist for the child and finding reading material about other families who have a child with ASD, were generally rated higher than more general family needs such as meeting with an imam, the need for help in deciding who will do chores, counselling or help in getting a job, and deciding on and doing family recreational activities.

Parents reported having high depression and anxiety levels which are relatively consistent with psychological distress profile of Arab families of children with ASD in other research (e.g., Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaidan, 2013; Alnazly & Abojedi, 2019) but higher than other UK parents (Hastings & Brown, 2002; Hastings, 2003). One might argue that the stigma of having a child with a disability is significantly more severe for parents in Arab cultures than other cultures, for example Western European, Latin American and South Asian, and so the perceived negative effect of having a child with a disability might be aggravated in Arab cultures, leading to high levels of psychological distress (Crabtree, 2007; Luthra 2010; Obeid & Daou, 2015).

The majority of parents reported high levels of relationship satisfaction with their spouse or partner, which may be in contrast to other studies of parents raising a child with ASD (e.g., Benson & Kersh, 2011; Hartley et al., 2012; Langley, Totsika, & Hastings, 2017; Sim et al., 2016). Al-Kandari et al. (2017) concluded that religion was the most frequently used coping strategy by Arab (Kuwaiti) mothers of children with ASD. Religion can provide a supportive role among parents of children with ASD and may be positively correlated with increased parental relationship satisfaction, and inversely correlated with relationship disagreement in parents of children with ASD (Ekas, Whitman, & Shivers, 2009; Parker, Mandleco, Roper, Freeborn, & Dyches, 2011). This might also explain the finding that the majority of parents reported no disagreement with their spouse over issues related to the child with ASD.

Consistent with previous research (e.g., Brown et al., 2011; Hartley& Schultz, 2015), the level of the child's behaviour problems was a significant predictor of total reported family needs. Previous research found that the most consistent and robust predictor of parental psychological distress levels, including depression and anxiety, was the child's behaviour problems (Abbeduto et al., 2004; Bromley et al., 2004; Estes et al., 2013; Obeid & Daou, 2015; White & Richard, 2004). In the present study, we found that the child's prosocial behaviour (not behaviour problems) was a significant predictor of parental psychological distress levels. In advance of replication, it is unclear whether this may be a cultural difference or simply a feature of the current sample of families. Associations between parental distress and both parents' health status and the number of children in the family are consistent with previous research (e.g., Magaña, 1999; Magaña, Seltzer, Krauss, Rubert, & Szapocznik, 2002). The finding that employment status was associated with lower parental relationship satisfaction may be a function of having long, exhausting, tightly scheduled days working outside the home and at the same time caring for their child with ASD. Employed parents might have less time to spend with one another, having more day-to-day demands imposed on them when balancing their different roles as a partner, a parent, and an employee. We also found that the longer families had been in the UK, the more parental disagreement over issues related to the child with ASD was reported, although it is not clear why this might be the case.

The study has provided an initial insight into support needs, psychological distress, and parental relationship of Arab families of children with ASD living in the UK. However, it is important to note that data were predominantly obtained from mothers. Therefore, future research intentionally sourcing data from the perspective of Arab fathers of children with ASD is needed. Understanding and identifying the needs of Arab families of children with ASD living in the UK may inform supports and services needed. For example, based on our findings, parents reported the need for information on how to teach their children with ASD. Additional research on Arab parent mediated educational intervention for their children with ASD is needed. In addition, support groups should be provided to the families to address their need to acquire information about current and future services for their children with ASD.

There is a limitation that should be acknowledged when interpreting and generalising the results of this study. It is not clear whether the families in our sample are representative of the population of Arab families that have a child with ASD living in the UK. In particular, the sample is small, and the response rate was essentially unknown as parents were recruited through various advertisements. This study needs to be replicated with larger samples.

Chapter 4: ‘I am a big thumbs-up with TEN-ID’ Special Educators’ Experiences of a Numeracy Curriculum for Pupils with Autism Spectrum Disorder

Abstract

The study explores the experiences and perceptions of ten educators from a special school who work with pupils with ASD on a structured numeracy curriculum used with their pupils. The special educators were interviewed using semi-structured interviews. Findings from this study indicate that taking part in the numeracy intervention was a valuable experience for both the educators and their ASD pupils. There was initial scepticism about the intervention, but this was transformed to conviction during the implementation period. Educators reported an increased sense of competence in their teaching skills which was evident in greater satisfaction and increased self-efficacy. Furthermore, there was a strong interest in continuing to use the numeracy intervention with pupils. Pupils' challenging behaviour was highlighted as a potential barrier to the use of the numeracy curriculum.

Introduction

According to the National Council of Teachers of Mathematics (2000), numeracy is one of the key domains of mathematics. Numeracy includes the ability to understand and represent numbers, relationships among numbers, for example place value, and number operations such as addition, subtraction, multiplication, and division), and using these concepts to form mathematical judgements and conduct complicated problem solving (Mclntosh, Reys & Reys, 1992). There is also an increasing awareness of the importance of mathematics for pupils leaving school with the required skills to function in the 21st century (Kilpatrick, 2001). Counting, telling the time, making payments, measuring and weighing, recognising basic graphics and schemes, and carrying out number operations are some types of fundamental uses of mathematical skills in daily life (Baglama, Yikmis & Demirok, 2017) that can also contribute to independent functioning (Su, 2003).

Mayes and Calhoun (2006) indicated that mathematics is a domain of academic consideration for pupils with Autism Spectrum Disorder (ASD). Nearly 25% of pupils with ASD have been found to have a mathematics learning disability (Mayes & Calhoun, 2006), compared with 3% to 14% of typically developing pupils (Gregoire & Desoete, 2009). Chiang and Lin (2007) examined the mathematical profile of pupils with Asperger Syndrome and high-functioning autism, and found that the majority of these pupils perform at a similar level to typically developing pupils. However, they noted that pupils with autism tended to perform more poorly on the Arithmetic subtest of the Weschsler Scales relative to their Full-Scale IQ, but this difference was small and indicated that mathematical ability was a relative modest weakness (Chiang & Lin, 2007). The difficulties pupils with ASD confront in mathematics may derive from differences in executive functioning involving planning, organisation, working memory, mental flexibility, attention, self-monitoring, and impulse control (Alloway, Rajendran & Archibald, 2009; Barnhill, Hagiwara, Myles & Simpson, 2000; Burney, 2015; Donaldson & Zager, 2010; Griswold, Barnhill, Myles, Hagiwara & Simpson, 2002; Happe, Booth, Charlton & Hughes, 2006; Hughes, Russell & Robbins, 1994). Furthermore, differences in language ability that correlate with ASD may also cause mathematics difficulties across several domains such as number - word sequencing, calculation, fact retrieval, and problem solving (Burney, 2015; Donlan, 2007; Zentall, 2007). Other researchers have found that pupils with ASD demonstrate a highly variable mathematics attainment profile (King, Lemons & Davidson, 2016). In Wei, Christiano, Yu, Wagner and Spiker (2015)'s longitudinal analysis of children with ASD between the ages of six and nine years, distinct profiles of mathematical achievement were identified, with 39% of children demonstrating average attainment across academic areas and 20% demonstrating average or above the national average skill in mathematics, while scoring below the national average for children in the general population on other tests of achievement.

Given the potential challenges, it is important that educators use the most effective methods for teaching mathematical skills to pupils with ASD (Su, Lai & Rivera, 2010). However, within the research literature on interventions with children with ASD, examining the best methods of teaching mathematics has received limited consideration (Su et al., 2010). In 2015, Barnett and Cleary conducted a review of mathematics intervention strategies for pupils with ASD. Eleven studies were included in the review: six used visual representation strategies such as touch point, video self-modelling on an iPad, and manipulatives to improve particular mathematics skills. The five remaining studies used cognitive instruction strategies such as counting-on and next-dollar strategies and response-repetition as an error-correction procedure. More recently, Spooner, Root, Saunders and Browder (2019) conducted a systematic review to examine evidence-based practices for teaching mathematics to pupils with moderate and severe developmental disabilities, including ASD. The main conclusion was that systematic instruction strategies can be used to efficiently teach mathematics skills for this population (Spooner et al., 2019). Systematic instruction strategies involve the use of explicit prompting strategies such as least intrusive prompts or time delay with feedback to teach a set of defined responses across time (Browder, Spooner, Ahlgrim-Delzell, Harris & Wakeman, 2008). In addition, the review results suggested that technology-assisted instruction, manipulatives, graphic organisers and explicit instruction may be considered as evidence-based practices in teaching mathematics to pupils with moderate and severe developmental disabilities (Spooner et al., 2019). Graphic organisers were defined as a diagram that helps pupils in conceptually understanding and solving a problem by demonstrating the related positions of the elements and their relationship to one another. Explicit instruction is defined as a series of supports and scaffolds, where pupils are guided through the learning procedure in small steps with explicit explanations of the targeted skill and provided with practice and feedback until mastery is accomplished (Spooner et al., 2019).

The effectiveness of mathematics interventions for pupils with ASD is an important topic for research. However, it is also crucial to understand the perceptions of pupils, educators and parents about instructional methods and interventions, since these may affect uptake of interventions in practice. Such perceptions also represent ‘social validity’: that the methods used to teach pupils with ASD mathematics skills are considered appropriate by key stakeholders including pupils with ASD, parents, and educators. However, there has been very little research addressing educators’ perceptions of mathematics interventions for pupils with ASD. Root, Browder, Saunders and Lo (2017) examined special educators’ and pupils’ views on schema-based instruction, with concrete and virtual manipulatives used to teach problem solving to three elementary pupils with ASD and moderate intellectual disability. Special educators and pupils were asked to complete satisfaction questionnaires. Pupils were asked to say ‘yes’ or ‘no’, or point to a smiling or frowning face on the questionnaire, to answer statements related to the outcomes of the intervention. Special educators were asked to rate 12 items related to the content and outcomes of the intervention on a 6-point Likert scale. An open-ended question was also used to obtain special educators’ feedback on the instructional methods and materials that were used. Educators reported that they felt the intervention improved their pupils’ early numeracy and word problem solving skills. All pupils reported that they liked the mathematics sessions and the materials that were used in concrete and virtual conditions.

O’Malley et al. (2013) conducted a survey with teachers who used an iPad as an instructional tool to enhance basic mathematics fluency of ten pupils with ASD or multiple disabilities. The survey included six items on a 5-point Likert scale to explore teachers’ perspectives on the intervention’s acceptability and effectiveness for classroom instruction. Findings revealed that teachers were satisfied with the outcomes and had recognised the intervention to be a success. Kasap and Ergenekon (2017) designed a questionnaire to identify mothers’ and teachers’ views on the instruction of verbal mathematics problem solving skills using a schema approach for three pupils with ASD. Mothers and teachers were asked to assess the competence of the skills studied in the research and outcomes. Mothers reported positive views on the study and teachers were satisfied with the schema approach.

We were not able to find qualitative research with educators using mathematics interventions with pupils with ASD. Using qualitative methods in intervention studies can provide fundamental data about how and why interventions do or do not work, how participants feel about interventions, and what factors might affect the success of interventions (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005; McDuffie & Scruggs, 2008; Pugach, 2001; Scruggs & Mastropieri, 1995). Moreover, Greenwood and Abbott (2001) indicated that teachers might be less likely to adopt and continue using interventions over time when they do not find interventions to be feasible, adequate, or related to their work. Thus, it is valuable to understand and reveal experiences of special educators on using mathematics interventions with pupils with ASD. In the present study, special educators were interviewed following an implementation of the Teaching Early Numeracy to children with Intellectual Disability (TEN-ID) curriculum with their pupils with ASD to examine their experiences of using the TEN-ID curriculum in their day-to-day work. As mentioned in Chapter 1 this study was conducted outside the Arab context. In addition to the main aim of this study, an additional aim was to assist me building my own knowledge of the TEN-ID intervention to be used later in an Arab context. Thus, the context of Arab cultures was not considered in this study.

Methods

Participants

Ten special educators working across five different classrooms in an autism department in a special school were interviewed. All had used the TEN-ID curriculum with 17 of their pupils for eight months. Five were teachers and five were teaching assistants (see Table 4.1). Participants had been trained in the use of the TEN-ID curriculum prior to its use in the classroom and prior to the start of this study. All names have been changed to protect the identity of the participants.

Table 4. 1 Demographic information of the participants

Participant's name	Participant's gender	Participant's role
Sarah*	Female	Teaching assistant
Jacob	Male	Teacher
Layla	Female	Teaching assistant
Kate	Female	Teaching assistant
Harry	Male	Teacher
Isla	Female	Teacher
Emily	Female	Teacher
Noah	Male	Teaching assistant
Jack	Male	Teaching assistant
Mary	Female	Teacher

*Pseudonyms have been used

Research Design

A qualitative approach using semi-structured interviews was used in the present study. Interviews were analysed using thematic analysis. Thematic analysis is "a method for identifying, analysing and reporting patterns within data" (Braun & Clarke, 2006, p.79). It was selected for its flexibility, capability for searching across a large body of data, and identifying similarities and differences across a data set. In addition, thematic analysis can produce unexpected insights (Braun & Clarke, 2006). A reflective diary was kept during data collection. After each interview, the first researcher reported her own thoughts and reactions to each interview as well as her perceptions of the participants' feelings based on their hesitations and the language they used. This helped in the interpretation of the underlying meaning of participants' reports, as well as highlighting instances where the first interviewer's own perceptions may have influenced that interpretation. As is often the case with qualitative research, the first researcher played an active role in both data collection and analysis, and her own experiences and biases will have influenced the wording to questions, the use of probes and how answers were followed up. The first and second researchers were known to the participants as they had trained them in using the TEN-ID curriculum and had provided mentoring visits during the intervention implementation.

Procedure

An interview protocol was developed by the researchers (see Appendix P, p. 360). Its aim was to explore special educators' subjective experiences of being part of the TEN-ID implementation. Data were gathered with regard to the educators' perspectives on using the TEN-ID curriculum with their pupils, how supported they felt during TEN-ID implementation, relevance to their pupils and to the wider curriculum, what they thought of TEN-ID outcomes, how they felt about taking part in the TEN-ID research project, and what they thought about wider implications of TEN-ID.

Ethics approval was obtained from the University of Warwick Humanities and Social Sciences Research Ethics Sub-Committee (HSSREC, ref: 119/16-17) (see Appendix Q, p. 363). The 12 special educators who had used the TEN-ID curriculum were invited personally, through an initial conversation one-to-one, to participate in the study and were given an information sheet (see Appendix R, p. 364) outlining the purpose of the study.

Ten of the 12 special educators agreed to participate in the current study. When the signed consent forms (see Appendix S, p. 368) were received, a suitable time was arranged with the participants to conduct the interview. All ten participants were interviewed during working hours by the first researcher, face-to-face in a meeting room at the school. In addition to written consent, verbal consent to audio record the interview was obtained just before the interview commenced. Nine agreed to be recorded. For the remaining participant, detailed notes were taken during the interview. The interviews lasted from 25 to 40 minutes, with an average time of 33.27 minutes.

The TEN-ID Intervention

TEN-ID was adapted from an existing mainstream numeracy curriculum, the Maths Recovery programme, and has shown some positive outcomes for children with developmental disabilities (Tzanakaki et al., 2014a; Tzanakaki, Hastings, Grindle, Hughes & Hoare, 2014b). Maths Recovery is a curriculum that was developed in Australia in the 1990s and designed for children in mainstream classrooms who were not meeting age-related expectations for mathematics (Wright, Cowper, Stafford, Stanger & Stewart, 1994; Wright, Stanger, Stafford & Martland, 2006; Willey, 2007). The programme involves five stages with progressive levels of sophistication: "1. Emergent (the child has few counting skills); 2. Perceptual (the child can count and do some additive tasks when objects are visible); 3. Figurative (the child can do additions but, although both quantities are known, the child still starts counting from one); 4. Counting-on (the child can use counting-on for additive tasks and counting-back to subtract); 5. Facile (the child can use more advanced strategies rather than counting-by-ones, such as incrementing and decrementing by tens)" (Tzanakaki et al., 2014a, p. 323). The adapted programme includes shorter instructions, prompting procedures, use of task analyses (breaking down complex tasks into smaller, more achievable steps), an additional generalisation step, clearly defined goals, and frequent use of reinforcement (Tzanakaki et al., 2014a).

The school involved in the study used the TEN-ID curriculum in its autism department in the school year 2017-2018. The pupils had been identified by the school's assistant head and head of the autism department as having the necessary skills to access the curriculum. Pre- and post-tests had been conducted to measure pupils' numeracy skills. The intervention was delivered by either class teachers or teaching assistants who worked in the pupil's classroom. Pupils had three sessions of TEN-ID per week, one generalisation session and one session of working on other maths education strands, as per the school's requirements.

Training sessions on TEN-ID were conducted by the first, second and third researchers with the teachers and teaching assistants who delivered the intervention. Throughout the course of the study, mentoring visits were provided by the first and second researchers to observe TEN-ID sessions and offer support, troubleshoot if needed and provide feedback.

Data Analysis

The recorded interviews were fully transcribed verbatim by the first researcher. To make sure that no data had been missed, the second researcher listened to the recordings and went through all the transcripts. The method of analysis used was informed by Braun and Clarke (2006): a) reading and re-reading the data, noting down initial ideas for coding (summaries of meaning or points of specific importance) on the transcript in the left-hand margin; b) generating initial codes and assigning data relevant to each code; c) sorting codes into potential themes; d) creating a thematic map that illustrates the relationship between codes, themes, and different levels of themes (main themes and sub-themes).

When conducting data analysis, the researcher becomes the instrument for analysis, making judgments about coding and theming the data (Starks & Trinidad, 2007). Each qualitative research approach has specific techniques for conducting, reporting, and evaluating data analysis processes, but it is the individual researcher's responsibility to assure rigor and trustworthiness (Nowell, Norris, White, & Moules, 2017). According to Braun and Clarke (2006) a rigorous thematic analysis can produce trustworthy and insightful findings. However, there is no clear agreement about how researchers can rigorously apply the method. Examining the overall trustworthiness of a qualitative study can be facilitated by for example keeping a reflective commentary and obtaining a peer examination/check and feedback over the duration of the study (Shenton, 2004; Nowell et al., 2017). Consequently, as mentioned above the first researcher kept recording her initial impressions of each interview and patterns appearing to emerge in the data collected. Further, a peer examination/check was obtained to increase incredibility and accuracy of data analysis. Therefore, master themes and the thematic map were checked by the second researcher and revised in discussion with the research team, until the first researcher was confident that all themes and related sub-themes had been identified. The second researcher was asked to create a mind map that included key ideas that came out from her reading through all the transcripts and then to check whether her key ideas in the mind map matched the themes that the first researcher had identified. As a result, the second researcher found that master themes and thematic map were comprehensive. However, she suggested some quotes were moved and some words changed. In addition, the interpretations of themes were collaboratively discussed with the research team throughout the period of analysis and during write-up of the research study.

Results

Four master themes emerged from the thematic analysis (see thematic map Figure 4.1): a) initial scepticism, to conviction, b) increased sense of competence, c) recognition of the potential of TEN-ID curriculum, and d) pupils’ challenging behaviour as a potential barrier to TEN-ID implementation.

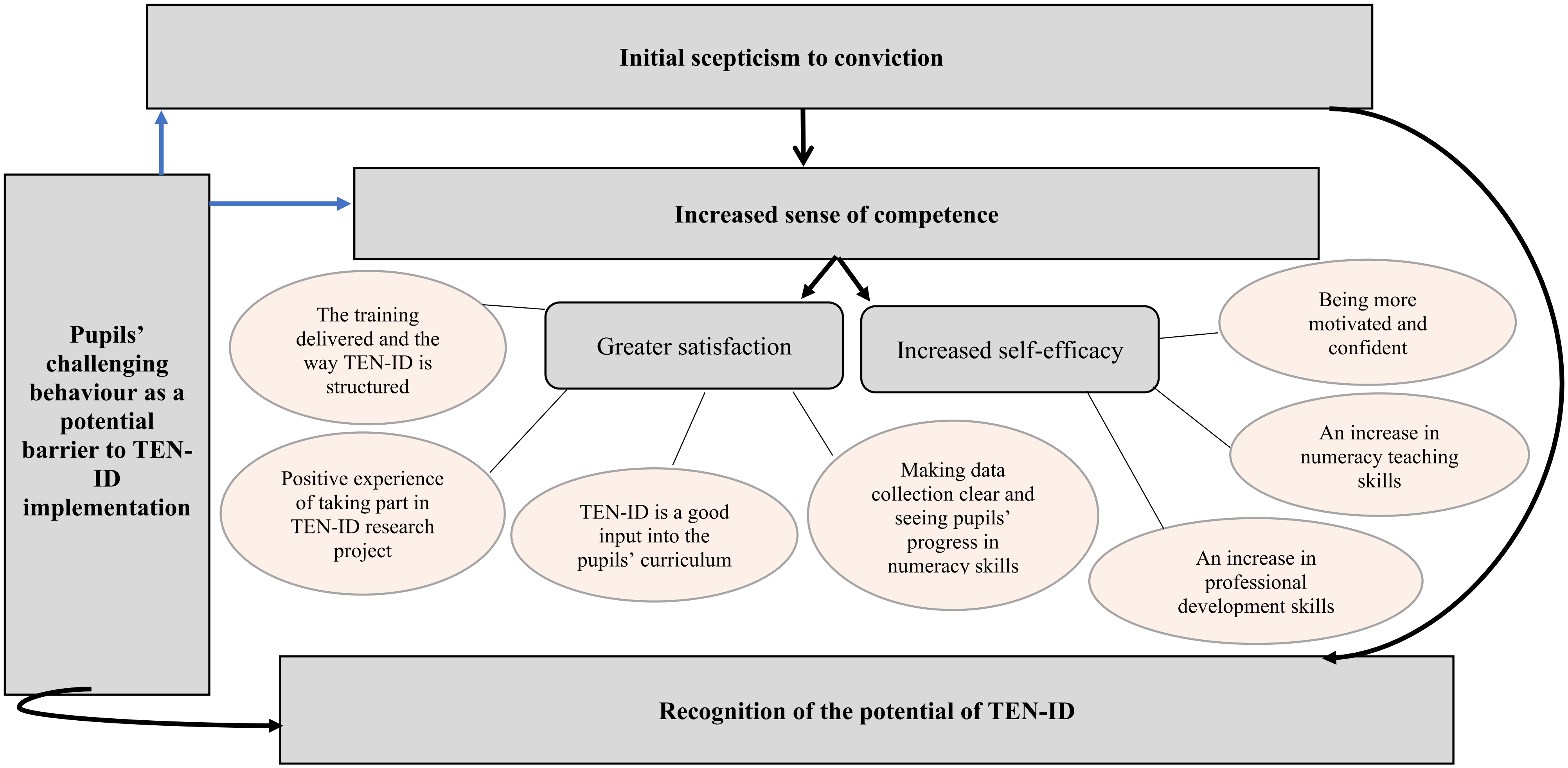

Figure 4. 1 Thematic map

Theme 1. ***'I was like-oh my God, I don't know what to do but when we do it and do it it's fine'*****: Initial Scepticism, to Conviction**

Six of the special educators stated that, at first, they were sceptical about the TEN-ID curriculum. Reasons for this varied. Three were sceptical because TEN-ID was a new teaching approach to them: 'Oh yeah, I was sceptical first, I am with most new things' (Emily) and it required a lot of preparatory work 'okay. So, initially [Mm] I was a bit unsure because it's a lot of paperwork, a lot of targets, a lot of getting set up' (Mary). A teacher also reported that the concept of TEN-ID curriculum and its subsequent implementation with pupils was initially daunting 'Yeah, [Mm] quite daunting at first kind of understand, trying to understand everything put together' (Jacob).

There were doubts about whether pupils could gain mathematical skills using this new teaching approach and had the ability to achieve TEN-ID's targets 'How you would see a target, think-oh this is impossible[Mm] yeah, some of the skills I didn't think they are be able to achieve-they are doing, they are understanding' (Mary). Recording all required data was reported as a concern at first and that this might affect the teacher's time with the pupils 'So, in the beginning I was concerned that all the recording, even though it actually was not that much recording, it appeared to be. So, in the beginning I was worried all recording will take over the time that we have the pupils and that has not happened' (Emily). Some initially saw TEN-ID as a dull and repetitive approach, although this view changed after implementing it with pupils: 'I've worked with two different sets of staff with doing this kind of approach of teaching [Mm] initially all of them were a bit like-uh, it's boring, repetitive but all of them now prefer it, because they see the difference that it makes' (Mary).

All the initial scepticism about TEN-ID curriculum dissipated over the course of the intervention ‘but when you start actually sitting down and actually doing it, it all makes sense’ (Jacob). Similarly, Mary reported that ‘when you actually see the difference it makes and the progress the pupil can make with this kind of approach- it changes your opinions’. Mary and Layla were impressed with how much their pupils had progressed, having initially thought that their pupils did not have the abilities to learn new numeracy skills and, consequently, not having tried to teach them ‘when they know how to count, and they recognise numbers, I was amazed to see- my God like- they are able to do it and we didn’t give them the chance to do that’ (Layla), ‘Like the domino cards with the air, doing pattern- it’s almost there but that we never thought they’ll be able to do’ (Mary).

Theme 2. ‘*I know what I want to do with teaching maths to special needs children’*: Increased Sense of Competence

With increasing conviction, the educators reported an increased sense of competence. Educators’ sense of competence was evident in the following sub-themes: greater satisfaction and increased self-efficacy.

‘I am a big thumbs- up with TEN-ID’: Satisfaction from taking part in TEN-ID intervention.

All the educators indicated their satisfaction from taking part in the TEN-ID intervention. Satisfaction was evident in the following elements: a) satisfaction from the training delivered and the way TEN-ID is structured, b) satisfaction from making data collection clear and seeing the pupils’ progress in numeracy skills, c) satisfaction that

TEN-ID is a good input into the pupils' curriculum, and d) satisfaction from taking part in the TEN-ID research project.

Satisfaction from the training delivered and the way TEN-ID is structured.

The educators indicated that training on the TEN-ID curriculum was clear and provided pertinent information. Jack reported that 'it was very well delivered, and it was well constructed'. He also mentioned that 'the training has been very [Mm] concentrated on us delivering it and what we need to do. There was good explanation why we are doing stuff, why we are doing these things and the theory behind it' (Jack). Sarah reported that being told and therefore understanding the reasons behind implementing TEN-ID curriculum with pupils was motivating for her as they are not always given that level of understanding with other interventions used in the school: 'we understood why we are doing it, which we're not always told but it certainly gives us motivation to actually – okay, this is what we're doing it for'. There was also a satisfaction about the practical element of the training. The educators stated that doing some activities during the training on the delivery of TEN-ID's targets and viewing videos showing good practice gave them a clear idea of how exactly TEN-ID is meant to work: 'Yeah showed us activities. Exactly how we should do it with the pupils, that was really good because gave me a clear idea of what I need to do' (Layla).

The structure of TEN-ID curriculum was described as being a positive aspect. The educators appreciated having structured and plan-based teaching which involves all targets and associated teaching resources, as well as a step by step process for teaching those targets and rewarding correct pupil responses 'I find easy [Mm] having more work-based targets in a folder. I find easy knowing- right there is work, we have all equipment that we need for each target in our boxes and literally rewards, [pause] our resources and the documents all together. So, it is literally straight into work, there is no faffing, no get in this, no get in that, folding things – it's work and it's straight, it's done for the kids as well' (Mary). Kate reported that she could use TEN-ID structure and technique with other pupils 'to have like structured or maths and structured [Mm] like English targets and stuff like that [Mm] personally for myself I can go on to use this even with my own child'. In addition, educators stated that their pupils enjoyed the way that TEN-ID session is delivered, which was using 'reward'-based learning 'they respond really really well to the structure of task-token-task-token and then reward at the end' (Sarah) and the way that this structure made the pupils more motivated and engaged in learning numeracy: '[Mm] she knows she gets an iPad… at the end of it, she knows what she's got to do, so that's been really really good in a way of getting her' (Sarah).

Educators were also positive about the materials provided: 'The materials are useful and brilliant. They match the targets that help to deliver the session' (Isla) 'but definitely what we have used has [pause] it worked, and it worked well for our highest pupils and our lower pupils' (Sarah).

The support received with the mentoring visits provided by the first and second researchers during TEN-ID implementation was also praised. Isla said 'The mentoring visits are very useful because you guys were able to give ideas how to implement the targets, able to give ideas how to adapt some targets. For example, you gave me ideas how to help [pupil's name] on doing chopping target, especially he has problem with his motor skills during the day'. Similarly, Noah reported that 'it was great, you were there to give advice when needed. When I was doing something wrong and you noticed you put me right, which is, that's perfectly normal and that's good, that's good practice on your behalf and especially for the staff that helped deliver it'. In addition to the helpful aspects of the mentoring visits in delivering TEN-ID curriculum, Harry observed that mentoring visits were also helpful outside TEN-ID context '[Mm] I found them useful as sometimes - you know - very useful because you guys spot things we don't sometimes. For examples [researcher name] suggested just moving [a pupil's name] from one side of the table to the other side, so he wasn't looking outside of the window-it's not just about TEN-ID'. Being observed by the researchers during the mentoring visits did not impact the educators negatively: 'I've never found under any pressure when I was being observed' (Jack). However, one teaching assistant reported that being observed was daunting at first as he did not want to deliver TEN-ID incorrectly, but said that over the time the mentoring visits made him more confident in delivering TEN-ID: 'But you guys being there was daunting as first, I felt really nervous because I didn't want to do it wrong because-but no it's good, it's really-having you ladies there made, gave me a bit more confidence over the time–you know–when I first started I was a little nervous but yeah no it's good' (Noah).

Feedback from the researchers during the mentoring visits was reported as helpful, constructive, collaborative, and encouraging 'it's always useful to know [Mm] whether you're doing good or bad. It's always useful to know [yeah] and it's always useful when it's a regular update to just make sure you're going on the right path, because when you teach somebody you don't want to teach something that's wrong-so, it's always useful. And it's always encouraging as well' (Kate). Sarah also reported that 'it's always - it's not just like you doing this wrong and you doing that wrong, it's always like - this isn't quite to script, this is what you can do instead or this isn't working, how about this. It's not just negative, it's very much collaborative and constructive or this is working really well we gonna incorporate that or carry on with that, it's fine'. Moreover, feedback during the mentoring visits positively affected educators' confidence in delivering TEN-ID 'I found the feedback useful as helps me follow and deliver targets. You are able to tell me what to do-do this and do that-do what it might be worked with pupils. So, this helps me to build my confidence over time' (Isla).

Satisfaction from making data collection clear and seeing the pupils' progress in numeracy skills.

The educators reported their satisfaction from making the data collection process clear: 'I really enjoy the way that you lay out the evidence, makes progress very clear'. (Jack). Similarly, Mary stated that 'in obviously mainstream children there's kind of a pattern but with our kids it's very different, so you're not actually told where to start and what the progression is, so, with this [raising a TEN-ID document] that gives you that information, that's what I've enjoyed' and Sarah reported that 'you know where you're going and what you're doing'. Due to making the process of data collection clear, the educators reported that they were able to recognise their pupils' progress through the TEN-ID curriculum 'I love being able to see the progress, which is I've missed this year with our new curriculum' (Sarah) 'it's nice to feel that you're making progress with-you know-to recognise kids' progress as well'(Harry). The pupils' numeracy skills were significantly improved, as noted by all the educators. For example, Jacob said that 'I think they are doing fantastic, I've seen a massive difference. Even looking last week, I was looking at a video of one of the pupils in October and then compare it to now'. Isla reported that 'I have seen an improvement yeah. They have made progress. They learn new maths skills like counting from thumb' and Mary stated that 'Yeah, he's flying through targets all the time'. Harry reported that his pupils enjoyed making progress ‘It’s great to see the kids making progress and enjoying progress’.

Satisfaction that TEN-ID is a good input into the pupils’ curriculum.

The educators’ responses suggested that TEN-ID provided them with a skills based approach to teaching numeracy that is a good fit with the pupils’ curriculum ‘[Mm] but it’s very effective teaching basic maths skills- like very basic maths skills, and I think it gives them the opportunity to teach skills that you might not think of when trying to teach maths and therefore we sometimes skip to try and teach them things that they might not understand without having done TEN-ID first’ (Harry). Kate said that ‘I think it’s [Mm] a very good input into the curriculum for the child that I work with anyway’. Also, Mary stated that ‘TEN-ID comes under the cognition and learning and obviously we have a lot of time in a curriculum for cognition and learning, so it filled in there’.

Educators were particularly satisfied to see that pupils were able to generalise the skills they learnt with TEN-ID. Sarah noted that ‘they’ve been able to count out money [Mm]-you know- identify numbers on a clock, which they couldn’t do before and because we’ve done numbers in TEN-ID’, while Isla reported that ‘Yes, I did notice generalisation of the skills they have learned. I remember that we were doing some counting with them and [pupil’s name] started to count from thumb like we do in TEN-ID’.

In addition, the educators believed that the TEN-ID curriculum had a positive impact on the pupils’ speech, sitting ability, attitude to learning and concentration during school work ‘I found that actually, by product of TEN-ID is actually some of the kids’ speech has actually improved, especially with one of the girls whose speech has come a lot more since we adopted the TEN-ID, has been noticed by parents as well' (Jacob), while Harry said that 'he's spending more time at the desk'. Emily reported the benefit of TEN-ID curriculum on her pupil's attitude towards learning 'So, in the beginning she would -as you know [laugh]-do all of the tasks but squeal the answers [Mm] loudly almost in protest and now [Mm] she smiles when she finishes the tasks'.

Satisfaction from taking part in TEN-ID research project.

Taking part in the TEN-ID research project was reported as a positive experience by the educators. Four teachers and five teaching assistants enjoyed taking part in the TEN-ID research project. 'I've enjoyed being a part of it. I've enjoyed, [Mm] and I liked what I've read and seen, I do enjoy teaching the TEN-ID' (Kate). Only one teacher reported that taking part in TEN-ID research project was frustrating: '[Mm] very interesting question. Well, it is frustrating at times. Sometimes my timetable has to be changed as a staff member maybe absent, I have safeguarding issues [Mm] so sometimes I can't do TEN-ID and stick to the mentoring visits' (Isla).

Moreover, the educators mentioned that TEN-ID being a part of a research project did not affect their day-to-day use of it 'but yeah in terms of it, we never felt any pressure that because it's a research project' (Sarah). In addition to this, Jack and Jacob demonstrated that they felt part of the project and welcomed the opportunity to give their opinions, for example regarding the teaching plans and during the mentoring visits: 'But, it's been really nice because sometimes people do research and they just go away and just create themselves but by yourselves actually getting teachers and TAs involved' (Jacob).

Furthermore, the educators were positive about the support provided and feedback during the research project. They also reported that the researchers were accessible, flexible and patient during the TEN-ID research project: ‘there is never a time when you feel like you’re stuck, and you have to go to seek - you or MA [researcher name] out, because you’re always available, you’re always there, which has always been helpful’ (Mary); ‘we are all colleagues working on this together - you know - we know what we’re doing with TEN-ID, you guys know what you’re doing with the kids, so it’s kind of like - we both know what we’re doing, coming from different angles but we meet in the middle and make it work’(Sarah).

‘I have learned different strategy of teaching numeracy to special needs children’**: Increased self-efficacy.**

Not only were the special educators satisfied from taking part in the TEN-ID intervention, they reported that using the TEN-ID curriculum in their classes was beneficial for them improving both their numeracy teaching skills and professional development skills.

The educators reported that using TEN-ID curriculum taught them more about numeracy as well as giving them new strategies for teaching numeracy skills to their pupils: ‘[Mm][pause] I learned more about maths. I never had a strong suit with maths [laugh] [Mm] in terms of teaching it before… but with the TEN-ID… I feel like I have more solid understanding of what they could be’ (Sarah). Isla said that ‘TEN-ID gives me different ways of thinking and having an alternative strategy to use’. In a similar vein, Mary stated that ‘I’ve definitely learned different ways of starting to teach maths’. Layla found that ‘teach them one-to-one, it’s really good it gives -you know- makes me see how a child is able to take, how can I like take so much from a child one-to-one’.

Implementing the TEN-ID curriculum also had a positive impact on educators' professional development skills. It had a positive impact on educators' self-reflection 'and over the time we've learned not to get frustrated when thing aren't working, which is good' (Jacob) and increased organisational skills 'I think I know the importance of having the teaching materials close and to hand and organised…. so it's highlighted to me how important it is to have things organised and to hand and then you can deliver more confidently' (Jack). In addition to this, TEN-ID implementation helped educators in being consistent in delivering tasks to their pupils 'We've got into a way all four of us are working, of a very similar way and we can swap groups. I can go and work with two other pupils and they are familiar with how I am delivering the teaching because it is very similar' (Jack). Interestingly, Kate mentioned that using TEN-ID taught her different ways and techniques of how to get pupils interested in learning. A teaching assistant also mentioned that using TEN-ID curriculum made him think how he is delivering other areas of the school's curriculum 'it's got me to think outside the box' (Jack) because TEN-ID taught him to think how to deliver a task in a way that pupils will understand. Moreover, Noah observed that 'doing TEN-ID taught me to make sure you realise how much help you might unknowingly give to the pupils and how much prompts you might unknowingly give'.

The educators also noted that they applied what they learnt from TEN-ID in teaching other areas of the school's curriculum: 'TEN-ID's taught me and my colleagues new approaches on how to teach other things, so generalisation not just for the pupils but for us we can take the skills we have learned from TEN-ID and apply them in other areas of our curriculum and in other parts of our day' (Jack). Furthermore, Sarah stated that she used the new teaching strategies that she learned from TEN-ID in teaching communication skills to one of her pupils who was not doing TEN-ID: 'it has helped in terms of trying to engage him in different ways, like I said, I've learned new ways of teaching maths, so that helped in ways of engaging him or even using that method to teach him something else, [Mm] like communication'.

As well as commenting on an improvement in numeracy teaching skills and professional development skills, the educators noted that they were more motivated and excited about teaching: 'taught me other ways to teach and it's also kind of got me excited a little bit about teaching… I'm like -yeah let's do something, a bit more enthusiastic about - okay let's think of different ways we can do this' (Sarah); 'it was encouraging as well and motivating when a child is achieving something' (Kate). Furthermore, the educators believed that TEN-ID had a positive impact on their confidence in teaching numeracy skills to their pupils 'It's certainly giving me more confidence teaching maths. I struggle with maths, I had to work hard in school so, yes, it's good and its certainly simplified things that are worrying for a teacher' (Harry); and 'it did impact on my confidence in doing Discrete Trial Teaching' (Isla). It is notable that a teaching assistant mentioned that TEN-ID increased his confidence because of not having to be directed by the class teacher 'when you are a TA and you're being directed from the teacher to do this and -you know- you haven't any impact in your teaching but then TEN-ID I found [pause] it was just– it, I felt differently, it wasn't necessarily being directed by the teacher…. But then that confidence went through the whole day to day' (Noah).

Theme 3. *'I would fight for them to have it'*: Recognition of the Potential of TEN-ID Curriculum

As mentioned before, all educators reported that their pupils benefited from using TEN-ID as there was not only an improvement in their numeracy skills but also an improvement in other domains of their life, for example their speech and sitting ability. Accordingly, they recognised the potential of the TEN-ID curriculum and strongly wanted it to continue to be used with their pupils: ‘they have to continue with it to see the progress and the difference it makes to them’ (Layla); ‘it would be really beneficial for them, even the ones are moving to 6th form… I think it’s proving that they are still learning, it’s proving that they’re still making progress which I know is very important, especially when they go into adult services. If they can prove they’re still learning, they’re more likely to get a place and TEN-ID has really shown, even for the lower ability -yeah, they can learn this, perfectly fine, perfectly capable with it [Mm] yeah, I think it would be a real shame, if we got rid of it’ (Sarah). Harry also mentioned that he had pupils in his class who did not have the required numeracy abilities to do TEN-ID, thus, it would be important to try to make TEN-ID accessible for them ‘I think it would be important to try and access the learners who are pre-emergent too, so it’s consistent and whatever age group they should be learning and starting to learn it, I think that would be important too’ (Harry). In addition, the educators would like to see TEN-ID being used in other departments in the school as it is beneficial: ‘I don’t see why it wouldn’t roll out, I think it is great’ (Jack). Most of them mentioned that TEN-ID would work with pupils in primary and secondary departments in the school as they are perfectly capable of accessing it, therefore, they will have the benefits that the pupils in the autism department had: ‘I think it would work for primary and secondary… I think the pupils are perfectly capable of accessing it and enjoying the benefit from the structure and all the benefits we’ve had in autism’ (Sarah). Similarly, Isla stated that ‘Yes, maybe with primary and secondary. I think they are more able at the number level, so they would appreciate it more. Also, their maths skills can be improved’. Jacob and Emily reported that TEN-ID would work in other departments in the school as an intervention to help pupils who struggle with a particular area of numeracy. On the other hand, Harry believed that pupils with severe intellectual disabilities would benefit from TEN-ID. He recalled a discussion with a parent of an 18-year-old pupil with severe intellectual disabilities that he used to teach him when he was 13 or 14 years old: ‘I spoke to a parent of a child I used to teach… and he still hasn’t learned how to count or still -and he can’t do the course that they want in a college because he can’t count, whereas if he had something like this and he doesn’t like to count now because he thinks he can’t do it-so if he had that intervention earlier then I think it would have benefited him’.

Theme 4. *‘The only issue with some of them was their behaviours’*: Pupils’ Challenging Behaviour as a Potential Barrier to TEN-ID Implementation

Pupils’ challenging behaviour was reported by some of the educators as the only real barrier to TEN-ID implementation. Challenges were experienced in facilitating the pupils to complete all targets: ‘she made it hard, refusing to do it or finishing it half way a through and then not wanting to continue in the afternoon to finish it’ (Noah) and doing TEN-ID consistently ‘there were some weeks when she would do it and some weeks she wouldn’t’(Emily). Moreover, Sarah reported difficulties with ‘not being in a very good mood, not wanting to work or just being very distracted’.

And yet, as mentioned before, some of the educators reported that using TEN-ID with their pupils helped in decreasing pupils’ challenging behaviour ‘from when we first started she would sit at the table and she would do the work, but it was smaller amounts and after a while she would become very agitated and would [pause] she would shout and scream her answers, instead of just talking and [pause] whereas now I noticed she will-she would do the tasks longer and more calmer’ (Emily). Kate believed that using TEN-ID with the pupil that she worked with had positively impacted his behaviour ‘when he came to us he had a lot of behaviour issues and stuff like that, but I think [pause] getting him to focus and do work, he’s just way better because he’s a completely changed child. Some of the behaviour issues that he had when he first initially came into the class and he doesn’t have them anymore and I think that is just focusing on the curriculum work’. Interestingly, Jacob reported that he used TEN-ID with some of his pupils to calm them down because they liked doing TEN-ID’s targets: ‘I even used the TEN-ID with some of the children to actually calm them down as well… They are sitting down, focused, energetic, they like the activities’.

The impression conveyed by participants was one of a shift in attitude from initial scepticism to conviction in the use of TEN-ID. This seems to have also been reflected by a changing perception of pupils’ behaviours: from challenging behaviours being a potential barrier to implementation, to becoming a means of pupil engagement. These shifts in attitude appear to either have been facilitated by, or led to an increased sense of competence on the part of educators. This increased sense of competence is reflected in part by satisfaction with taking part in the intervention, and the intervention itself, as well as the increased sense of self-efficacy that this brought about.

Discussion

This study represents the first qualitative exploration of special educators’ experiences of using the TEN-ID curriculum with their ASD pupils in a school setting. Analysis of the interview data indicated that using the TEN-ID curriculum with their ASD pupils was a valuable experience for special educators. Educators were at first sceptical about the TEN-ID curriculum, but this transformed to conviction during the implementation period. Educators were positive about TEN-ID, its practical elements, and its benefits for them and their pupils. Findings revealed that educators were satisfied with the training they received on TEN-ID. Training provided a good introduction to TEN-ID. Interestingly, educators highlighted the importance of knowing and understanding the principles behind TEN-ID implementation which then led them to be more motivated about delivering the curriculum to their pupils. Support provided during mentoring visits over the curriculum implementation period were reported as helpful and boosted educators' confidence in delivering TEN-ID to their pupils. In addition, educators liked having structured plans for teaching. Having clear data collection was also highlighted by educators as helping them to recognise pupils' progress with the TEN-ID curriculum. Educators also enjoyed taking part in the TEN-ID research project and appreciated being involved by having an opportunity to share their experiences.

Using the TEN-ID curriculum positively affected educators' numeracy teaching skills and professional developmental skills. Educators' responses indicated that they experienced increased self-efficacy. Teaching TEN-ID provided educators with a strong background in numeracy; gaining not only new strategies for teaching numeracy skills to their pupils but also techniques that helped in engaging pupils with learning numeracy. Reported increases in pupils' attending behaviour were likely due to including reinforcement systems during the TEN-ID teaching protocol. Interestingly, educators reported that using prompting and prompt-fading procedures taught them to think about how they teach other areas of the school's curriculum. Educators' professional developmental skills were also improved. For example, there was an increase in their organisational skills and being consistent in teaching. As a result of an improvement in numeracy teaching skills and professional developmental skills, there was an increase in educators' motivation for teaching and confidence in teaching numeracy skills to their pupils.

Satisfaction from taking part in the TEN-ID intervention and an increased self-efficacy reflected an increased sense of competence. In their definition of competence Johnston and Mash (1989) identified satisfaction and efficacy as the two contributing factors to a person's sense of competence. Existing research has also highlighted the links between satisfaction and efficacy.

In terms of pupils' learning benefiting from participation in TEN-ID, these educators indicated that pupils' numeracy skills were considerably improved and they were able to generalise the skills they learnt with TEN-ID. Pupils' learning extended beyond the planned intervention, with educators observing that pupils' speech, sitting ability, attitude to learning and concentration during school work improved. These improvements were likely due to the consistent implementation of an instructional routine. Moreover, these educators believed that using TEN-ID helped in reducing some pupils' challenging behaviour. However, some educators reported pupils' challenging behaviour was a potential hindrance to TEN-ID implementation.

Greenwood and Abbott (2001) indicated that teachers might be more likely to adopt and continue using an intervention, when they find it to be appropriate, feasible, or related to their work. This is consistent with the present study findings that all the educators expressed strong interest in continuing to use TEN-ID with their pupils as they recognised the potential of the TEN-ID intervention.

This study has a certain limitation that needs to be taken into consideration. The first researcher was involved in training the participating educators on the use of the

TEN-ID intervention and provided mentoring visits over the intervention implementation period. She also conducted the interviews with the educators. Therefore, caution should be applied to positive reports from educators regarding training and mentoring visits as bias may have been present. In addition, the role of the first researcher in the intervention as well as the interviews might be a limitation. Thus, the first researcher kept a reflective diary during data collection and discussed her own preconceptions to each interview with the second researcher in order to minimise this limitation.

Outcomes of the present study would be encouraging for educators and practitioners working in special schools and should provide valid information around experiences of being part of the TEN-ID intervention. However, further research is still needed, and a replication of this study with a larger group of educators who also working with different populations, for example pupils with learning difficulties, would be recommended.

Chapter 5: Parent Mediated Numeracy Intervention for Children with Autism Spectrum Disorder in Arab Families Living in the UK

Abstract

Research on teaching mathematics to Arab children with Autism Spectrum Disorder using parents as mediators is limited. The purpose of the present study was to carry out an initial evaluation of an adapted Maths Recovery numeracy programme with three children with Autism Spectrum Disorder, by training and supporting their parents to deliver the intervention over the course of eight weeks intervention. Using a pre-test post-test design, results from a standardised assessment revealed that the three children’s mathematical ability improved over the course of the intervention. Parents also described positive experiences of their training and of using the curriculum, especially mentioning how much their children had progressed in their understanding of mathematics. The study data show promising results and provide initial evidence that the adapted Maths Recovery programme can be adapted for a home context.

Introduction

Competence in mathematics has considerable implications for an individual's ability to achieve academically, to live independently, e.g., budgeting, scheduling, paying bills, to gain and sustain a job, and to engage socially, e.g., playing games (Sarama & Clements, 2009). According to the National Council of Teachers of Mathematics (2000), numeracy is one of the main domains of early mathematics skills. Numeracy refers to the ability to understand and represent numbers, relationships among numbers, for example e.g., place value, and number operations including addition, subtraction, multiplication, and division, and using these concepts to form mathematical judgements and conduct complicated problem solving (Mclntosh, Reys & Reys, 1992).

Children with Autism Spectrum Disorder (ASD) can demonstrate learning of fundamental and advanced mathematical skills (King, Lemons & Davidson, 2016). However, the mathematics attainment profile of children with ASD is variable (Charman et al., 2011). Children with ASD as a group have lower levels of mathematics skills compared to children generally (Wei, Christiano, Wagner & Spiker, 2015). Nearly 25% of children with ASD have been found to have a mathematics learning disability (Mayes & Calhoun, 2006), compared with 3% to 14% of typically developing children (Gregoire & Desoete, 2009), even though some children with ASD may have exceptional mathematics ability (Chiang & Lin 2007). A longitudinal study of individuals with ASD reported slower development rates in calculation abilities as compared to children with mathematical learning disabilities (Wei, Lenz, & Blackorby, 2012).

Some cognitive characteristics associated with ASD may explain some of the difficulties these children face with mathematics (Burney, 2015). For example, children with ASD may have deficits in visuo-spatial coordination, which is crucial for obtaining mathematics skills (Donaldson & Zager, 2010). Other researchers have reported that deficits in working memory, executive functioning and language development may influence children with ASD's attainment on mathematics skills (Barnhill, Hagiwara, Myles & Simpson, 2000; Donaldson & Zager, 2010; Griswold, Barnhill, Myles, Hagiwara & Simpson, 2002; Happe, Booth, Charlton & Hughes, 2006; Norbury & Nation, 2011).

Within the research literature on interventions with children with ASD, examining the best methods for teaching mathematics has received limited consideration (Su et al., 2010). Most existing research has focused on the best methods to teach an isolated mathematical skill rather than looking at how individual skills can be taught systematically as components of a comprehensive mathematics programme that teaches a wider range of skills. For example, Root, Browder, Saunders and Lo (2017) focused on how to use modified schema-based instruction with three elementary children with autism to teach the skill of mathematical word problem solving (see also Jowett, Moore and Anderson, 2012; Bouck Satsangi, Doughty & Courtney, 2013).

In terms of teaching methods, there is some evidence that systematic instruction strategies can be used to teach comprehensive mathematics skills to children with ASD (Browder, Spooner, Ahlgrim-Delzell, Harris & Wakeman, 2008; Spooner, Root, Saunders & Browder, 2019). Systematic instruction has several important components including: using clearly defined teaching goals, in other words, 'operationally defined' targets, using a system of least to most prompts and prompt-fading techniques, specification of error-correction techniques, data collection to monitor progress, and generalisation (Browder et al., 2008; Spooner et al., 2019).

Tzanakaki and colleagues (2014a) adapted an existing numeracy curriculum, the Maths Recovery programme, to meet the needs of children with learning difficulties and ASD. The adapted programme incorporated elements of systematic instruction by including shorter instructions, prompting procedures, use of task analyses (breaking down complex tasks into smaller, more achievable steps), additional generalisation steps, clearly defined goals, and frequent use of reinforcement (Tzanakaki et al., 2014a). Maths Recovery is a curriculum that was developed in Australia in the 1990s and designed for children in mainstream classrooms who were not meeting age-related expectations for mathematics (Wright, Cowper, Stafford, Stanger & Stewart, 1994; Wright, Stanger, Stafford & Martland, 2006; Willey, Holliday & Martland, 2007). The programme covers a comprehensive range of numeracy skills from very early, e.g., counting 1–20, recognising numerals 1–10, being able to count up to 20 items, counting using fingers, to advanced, e.g., counting by 10s and 100 s to 1000, addition/subtraction of two-digit numbers, word problems involving multiplication/division (Tzanakaki et al., 2014a).

There have been two evaluations of the adapted Maths Recovery (MR) intervention. In the first study, researchers used pre- and post-test assessments to evaluate the adapted MR curriculum to teach early numeracy to six children of primary age with a diagnosis of autism, in a specialised classroom in a mainstream school (Tzanakaki et al., 2014a). Results indicated that over a 20-week period, all children made substantial gains in their numeracy knowledge and skills, and those gains were maintained over time. The second study involved a pilot randomised controlled trial of the adapted MR curriculum with 24 pupils with severe intellectual disability and/or ASD (Tzanakaki, Hastings, Grindle, Hughes & Hoare, 2014b). Results showed that over a 12-week period, the adapted MR curriculum was more effective in teaching numeracy to pupils than the school's numeracy as usual curriculum, and results of the intervention were maintained over time.

These studies indicated that staff in special schools can be trained to deliver the adapted MR curriculum. However, due to staffing issues the fidelity of the intervention implementation was compromised. Staff could not have the availability to deliver the intervention (Tzanakaki et al., 2014a; Tzanakaki et al., 2014b). In addition, not all children with ASD attend special schools. Consequently, these issues may confine the number of children with ASD who might benefit from the adapted MR curriculum. Training and involving parents to support their child's numeracy intervention potentially increases the number of children who might benefit and is valued in policy.

Other research has demonstrated that parent mediated interventions, both in the field of health and education, can have a positive influence on outcomes for children with ASD (Kasari et al., 2014; Kaiser, Hancock & Nietfeld, 2000; Sofronoff, Leslie & Brown, 2004; Beaudoin, Sébire & Couture 2014). Parents are available to practise skills with their child throughout the day and across situations (Nevill, Lecavalier & Stratis, 2018). Fishel and Ramirez (2005) reviewed 24 studies investigating parents involved with interventions with school-aged children generally, and found that parental involvement was strongest for interventions targeting primary school children, working on a single academic domain including reading and mathematics skills, through home-based parent tutoring. According to McConachie and Diggle (2007), parental involvement in implementing intervention strategies designed to support their children with ASD has long been noted as useful. The potential advantages are enhanced child's skills, increased parental knowledge of ASD, improved maternal communication style and parent child interaction, and decreased maternal depression (McConachie & Diggle, 2007).

Providing parents with the skills to efficiently manage their child's developmental delays can also enhance the parents' sense of competence, reduce stress, and increase family coherence (Koegel & Koegel, 2002). Consequently, it is of interest to design models for parent-mediated intervention that are both attainable for parents to use and lead to improved developmental functioning (Nevill et al., 2018). Over the last 15 years, there has been an increased emphasis on research on parent mediated interventions in ASD (Nevill et al., 2018) including a number of reviews on the effectiveness of parent mediated intervention for their children with ASD (e.g., Beaudoin et al., 2014; McConachie & Diggle 2007; Oono, Honey & McConachie, 2013; Lang, Machalicek, Rispoli & Regester, 2009). Research on parent mediated intervention to children with ASD has stressed that parents should be trained using naturalistic methods which would be feasible to use in the home context (Brookman-Frazee, Stahmer, Ericzen, & Tsai, 2006). In addition, parents should receive ongoing supervision and support from researchers/professionals over the period of intervention implementation (Oono et al., 2013). However, research of parent mediated intervention in ASD tend to focus on mediating communication and social skills. Consequently, we were not able to find research on parent mediated numeracy intervention in ASD.

The primary aim of the current study was to carry out an initial evaluation of the adapted MR curriculum by training and supporting parents to deliver the intervention. A secondary aim was to contribute to the literature on teaching skills to children who come from an Arab background. In Chapter 2 we found four studies investigating the impact of intervention strategies on improving social and communicational skills of Arab children with ASD (Al Shammari, Daniel, Faulkner & Yawkey, 2010; Alshurman & Alsreaa 2015; Al zyoudi, Sartawi & Almuhiri, 2015; Fteiha, 2016), but none targeting numeracy skills. Thus, there is an evidence gap on methods to support academic interventions generally in Arab contexts, but also specifically with parents as mediators.

This study was essentially a modelling study focused mainly on the intervention, in other words, the main purpose was to explore whether the adapted MR curriculum could be delivered in the home context and potentially in Arabic. According to Craig et al. (2008) modelling a complex intervention prior to a full-scale evaluation can provide important information about the design of both the intervention and the evaluation. In addition, modelling studies can identify weakness and lead to refinements, or can show that a full-scale evaluation is unwarranted. It is important to start thinking about implementation at an early stage in developing an intervention and to ask the question ‘would it be possible to use this?’ before embarking on a lengthy and expensive process of evaluation (Craig et al. 2008). Indeed, it was the first time that this intervention had been used in the home context, and with an Arab population of mothers and their children. Therefore, conducting a modelling study could provide information on what would need to be considered in any future delivery of the intervention in this context. Conducting a small modelling study was needed as we were changing: the delivery agents (mothers), the context (home), and some other dimensions of the intervention (the training, family culture, and telephone rather than face-to-face support). Consequently, we aimed to explore how all these elements might work.

Evaluation Method and Intervention Description

Participants

Three boys with a diagnosis of ASD and their mothers participated in the study (after receiving approval from the University of Warwick Humanities and Social Sciences Research Ethics Committee (HSSREC, ref: 09/18-19) (see Appendix T, p.

369). Ali (all names are pseudonyms) was aged 5 years and 4 months, Rami was aged 5 years and 7 months, and Hani was 6 years and 1 month. To be eligible to participate in the study the children had to be between 4 and 15 years old, have an ASD diagnosis (as confirmed by parental report only), have few counting skills, e.g., could name some but not all numerals in the range one to ten, and have the necessary prerequisite skills to be able to benefit from the intervention, e.g., sitting willingly at a table to engage in learning tasks for short periods of time up to 15 minutes, be able to follow simple one step instructions, e.g., clap hands, and be able to repeat back simple sounds and words that they hear.

The three children had some verbal abilities ranging from using a few single words to being able to talk in full sentences. The children were attending special schools. All had been identified by their mothers as requiring support with mathematics.

Parents were eligible to participate in the study if they self-identified as originating from one of the following 22 Arab League states: Algeria, Somalia, Egypt, Libya, Sudan, Tunisia, Morocco, Mauritania, Djibouti, Bahrain, United Arab Emirates, Oman, Kuwait, Qatar, Saudi Arabia, Yemen, Jordan, Syria, Iraq, State of Palestine, Lebanon, and Comoros. Given that families from these countries may use Arabic at home or create bilingual environments, the intervention was available in both English and Arabic. Two mothers used English at home with their children, and one used Arabic. Parents were given an information sheet (see Appendix U, p. 370) outlining the purpose of the study. Consent forms (see Appendix V, p. 375) were also provided to parents.

A variety of different routes were used to contact Arab parents of children with ASD in the UK such as via autism and child disability charities, or special schools that provide services to children with autism, and online via Facebook, Twitter and

WhatsApp groups. It should be noted that some of the parents that we contacted declined to take part in the study. Reasons for declining included parents view that schools sufficiently supported their child's numeracy skills thus there was no need for an additional numeracy intervention. In addition, parents mentioned that they did not have time to teach their children at home due to being busy with domestic chores. Further, due to privacy concerns, parents did not feel comfortable participating in research and sharing personal information with an unknown researcher.

Setting

Teaching sessions were conducted in the child’s home in a place chosen as appropriate by the child’s mother, for example at a table in the child’s bedroom or in the living room. The children usually practised the numeracy intervention with their mother sitting at a table facing them. Teaching sessions took place outside of school hours: before or after school, and at weekends.

Numeracy Intervention

The adapted Maths Recovery intervention as developed by Tzanakaki and colleagues (2014a, b), now known as Teaching Early Numeracy for children with Developmental Disabilities (TEN-DD)[2], was used. Teaching plans for the first teaching phase, known as the Emergent stage, were translated into Arabic by the first researcher (see an example of the teaching plan for the first target of the emergente stage in the Appendix W, p. 377). A bilingual individual who was experienced in mathematics was asked to check the translation. The final Arabic version for the Emergent stage materials was produced after obtaining comments and feedback from the bilingual individual. Finally, two experts in the Arabic language approved the Arabic version of the manual

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[2] The name of the numeracy curriculum was changed from TEN-ID to TEN-DD by the time of this study

and agreed that it was written in Arabic of a high standard. One final modification to the original TEN-DD teaching plans was that suggestions for generalisation were modified to be more appropriate for the home context.

The Emergent stage teaching plans contain different sections including a description of the materials that the parent needs to use to teach the target skill that should be gathered before starting the session. In the teaching procedure section there is all the information necessary to know how to teach the child, including a description of the teaching set-up, the instructions to deliver, and the response that should be expected from the child. There are also some suggestions for how to set up situations to encourage the child to use learned skills in different situations, i.e., how to generalise skills. Further, in the prompting section there are some ideas on what to do if the child struggles with a specific target or does not respond. The level that the child needs to reach to move on to the next target is also included. An example of a teaching plan for the target 'saying short forward number word sequences from 1 to 20' is shown in the Appendix X (p. 379).

Overview of Teaching Procedure

Mothers were advised that four 20-minute TEN-DD sessions should be conducted each week, i.e., a total of one hour 20 minutes per week. Children worked on three numeracy targets from the first three key topics of the Emergent stage at any one point in time. Mothers presented the task to the child without prompting, and a correct or incorrect response was recorded on the data sheet for the skill. The mastery criterion for each skill was three correct answers across three consecutive sessions. Mothers were also told that a variety of items and activities should be used as reinforcers for the child, based on their preferences. Story books, small toy cars, animals, building blocks, and colouring pencils were some of the items that were used. In addition, a token board system was also utilised. Tokens were placed on the board, contingent on appropriate working. When all the tokens had been acquired, the child could choose one of the reinforcement items or activities, and engage with it for a few minutes. Generalisation was included for every task. Mothers were advised that skills learned in the structured teaching sessions should be practised in a variety of different situations, e.g., in different places, with different family members, using different materials and a variety of instructions.

Although it was not possible for the researchers to provide overlaps to check that mothers were delivering the recommended number and duration of sessions per week, duration data sheets were used to try to ensure some fidelity of implementation. Thus, when sessions were delivered, mothers recorded on a provided session log the duration of each session. During telephone support sessions (see below), mothers were reminded about recording data on the session log.

Teaching Materials

Each child had a TEN-DD folder which contained, in both English and Arabic versions: a) target lists for the first three key topics of the Emergent stage: verbal counting, written numerals 1-10 and counting visible items up to 20; b) a skill tracker for the child was also included alongside the target list to record data on it by putting (✔) for a correct response and (✕) for an incorrect or prompted response. When the child reached mastery, meaning three correct responses in a row, parents were instructed on how to record the date of mastery on the skill tracker and to then introduce a new target to the child; c) teaching plans for the first three key topics of the Emergent stage; d) duration data sheets (session logs). We tried to make the process of data collection simple and clear for the mothers, as special educators in Chapter 4 mentioned that having clear data collection helped them to recognise pupils' progress with the curriculum which in turn motivated them.

We provided for each child a box of teaching materials that are used in the TEN-DD curriculum. Each box included counters of different colours, number lines, for example 1-3, 1-4, 1-5, etc., numeral tracks (number lines with a small cover for each numeral), and numeral cards 1-10.

Mothers were advised to use a token economy system, where points or stars were given to the child as they engaged with the sessions and completed targets. These could then be exchanged at the end of the session for preferred items and activities. These reinforcers were identified based on mothers' knowledge of their child's preferences such as watching TV, playing with an iPad. The use of a token economy system was based on Chapter 4 findings. Special educators reported its benefit for the pupils. They mentioned that the token economy system made the pupils more motivated and engaged in learning numeracy.

Parent Training and Support

Prior to the beginning of the intervention, we conducted one three-hour training session with the three mothers who took part. The training was delivered on two separate occasions. For the two mothers who could speak English fluently, their training was delivered in English by the first and the third researchers. For the third mother, who had very little spoken English, her training was delivered in Arabic by the first researcher. The training sessions were conducted in the mothers' homes. The children were not present at the training.

During the training, the TEN-DD teaching plans were described, including suggested teaching strategies, directions for data collection, and the list of materials that would be needed for teaching the children. A focus of the training was also to model for mothers how to deliver the teaching, including how to effectively deliver instructions, how to reinforce the child for correct responses, how to correct errors, and how to deliver prompts effectively. The results in Chapter 4 clarified the benefits of the practical element of the TEN-DD training. The special educators valued doing some activities during the training on the delivery of the TEN-DD's targets and how this provided them a clear idea of how exactly the TEN-DD is meant to work. Therefore, a large proportion of the training involved the mothers role-playing different teaching scenarios and receiving feedback from the trainers regarding their teaching skills. As the mothers had no prior teaching experience, every attempt was made to deliver the training in an accessible format using plain, non-technical language and explanations.

The researchers were not able to conduct any teaching sessions with the children or provide any 'overlap' sessions with mothers while they were implementing the intervention with their child. Thus, for all children, after this initial training, mothers conducted the intervention without further opportunities for modelling and feedback on implementation. Weekly telephone support sessions throughout the intervention, however, were provided to the mothers by the first researcher to discuss individual children's progress and any problems that may have arisen during teaching. A standard format was followed during the support sessions. 'How to get started' with teaching was discussed in the first support session only. Each subsequent session focused on: a) completing the recommended four sessions per week, and a check on how many sessions had been completed; b) practical solutions to help establish a routine for teaching session delivery, for example was there anything the mother needed to do or put in place to get started with the sessions, such as getting into a routine of same time and place every session, either immediately after breakfast or on return after school; c) checking that the child was moving onto new targets only when it was appropriate to do so, i.e., only when they had achieved three correct answers in a row; d) troubleshooting solutions if the child was not making expected progress: mothers were advised on how to break down teaching targets into smaller, more achievable steps, specific prompting and prompt-fading procedures and frequent use of reinforcement; e) reminding mothers about the importance of generalisation. If they has not been practising generalisation they were given specific suggestions they could try based on the targets the child was working on, for example singing songs that involved forward number word sequences such as '1-2-3-4-5, once I caught a fish alive, 6-7-8-9-10 then I let it go again'. The mothers were also encouraged to describe their own ideas for generalisation that they might find easy to do with their child.

During the telephone support sessions, the first researcher suggested to mothers that they could be put in contact with each other, as it was hoped that this would help to provide some peer support and encouragement that would bolster the impact of the intervention. Notes from each telephone support session were taken and sent to the mothers so that they could easily access the advice given and issues discussed.

Assessment of Children's Numeracy Skills

The children's mathematical skills were assessed using The Test of Early Mathematics Ability, 3rd edition (TEMA-3, Ginsburg & Baroody, 2003). This is a standardised test designed to measure mathematical ability in typically developing children aged between 3 years 0 months and 8 years 11 months, but it can also be used with older children with mathematical learning difficulties. The test involves different items of mathematics tasks, such as verbal counting, reading and writing numbers, saying the number that comes after a given number, and story problems involving additions or subtractions. TEMA-3 provides a raw score indicating the number of items the child answered correctly. The standard score of the test is called the Math Ability score with a mean of 100 (SD = 15). A Math Ability score between 90 and 110 is described as ‘average’ for a typically developing child. In addition, the test also provides an Age Equivalent Score, or ‘mathematical age’. For example, a mathematical age of 60 months shows that the child meets the level of a typical five-year old (Tzanakaki et al., 2014a; Tzanakaki et al., 2014b).

The TEMA-3 has two parallel forms, A and B. Each of the three children was tested before intervention with form A, and at the end of the intervention period after eight weeks with form B. It should be noted that the third mother was asked to deliver the TEMA-3 tasks to her child under the supervision of the first researcher. The first researcher explained to the mother how to deliver each task using Arabic. Arabic is a single written language but has many spoken dialects, and many different regional variants of some words can be found (Arabiat, Elliott, Draper, & Al Jabery, 2011). The first researcher and the child spoke with different Arabic accents. Therefore, this child’s assessment was delivered by his mother to avoid any misunderstanding or confusion by the child. In addition, the mother mentioned that her child might find it difficult to respond to an individual whose appearance, conversation, and conduct are distinct from his personal knowledge.

Evaluation findings

Implementation Data

All children received the intervention for eight weeks. The summary data for the number of recorded sessions and the total time spent receiving the intervention are presented in Table 5.1. Rami received 1 hour and 12 minutes more than the recommended total duration of teaching time over the course of the study, Hani received close to the recommended amount of teaching time, but Ali's parents went on holiday for three weeks during the intervention period and he did not receive the intervention during this time. Consequently, he received the least teaching time and less than the recommended duration.

Table 5. 1 Children's individual teaching profile

Child	**Weeks**	**Number**	**Hours/Minutes**
	Intervention	Recorded sessions	Total duration
Ali	8	20	5h 30m
Hani	8	31	9h 30m
Rami	8	33	11h 52m

In terms of the number of sessions per week (see Table 5.2), Rami received the recommended number of sessions per week with one session more than the recommended sessions in week 3. Hani received fewer than the recommended number of sessions in weeks 1 and 8, and more than the recommended number of sessions in weeks 3 and 4. Ali did not receive any teaching sessions for three weeks; however, in weeks 1 and 6 he received more than the recommended number of sessions per week.

Table 5. 2 Frequency of sessions per week over 8-week intervention period

Child	**Weeks**							
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Ali	5	4	3	2	0	5	0	0
Hani	3	4	5	5	4	4	4	3
Rami	4	4	5	4	4	4	4	4

Telephone Support Sessions

The mothers received weekly telephone support sessions of approximately 20-30 minutes each; Ali's mother did not receive the support sessions during the family holiday. Suggested solutions about difficulties related to the intervention and to the child's behaviour motivation and attention were provided to the mothers. Questions about the intervention included Hani's mother asking: 'Hani omitted number 3 when he counted from 1-5. I tried with him many times, but he is still not saying it! Any ideas I might try with him?'. The suggested solution was provided by asking Hani's mother to repeat the instruction and say the omitted number in a very loud voice. Hani's mother also asked: 'I worked with Hani on counting dots (1 - 6) forwards and backwards; he was fine with counting forwards, but he struggled when counting backwards from 6, so how can I help him?'. The mother was asked to prompt Hani by saying 'sss' for six and initially to gesture or hand-over-hand prompt to touch the last dot. Questions concerning child's behaviour included Rami's mother asking: 'yesterday, Rami wasn't concentrating at all-I felt that he was bored! I tried to encourage him…I wonder how I can make it fun for him?'. The suggested solution was to use fun materials such as toys, or giving Rami brief breaks for active play such as bouncing on a ball, or providing a quick stretching or jumping break.

The telephone support sessions also focused on generalisation strategies. Generalisation examples included Hani's mother mentioning: 'there were ten spoons at the table, his dad asked him to count them and he counted them correctly', and Rami's mother said: 'I asked him to give me five cookies… he actually did it'.

Children's TEMA-3 Scores

Pre- and post-intervention scores for each child on the TEMA-3 are presented in Table 5.3. All three children made gains on this test by the end of the intervention. Rami made the most gains with 18 points, and reached an age-appropriate level of skill, reflected in a standard score of 89. Ali and Hani made an improvement of seven and six standard points respectively. Age Equivalent scores indicated that prior to intervention, Ali had a maths age of four years and six months, Hani had a maths age of three years and Rami had a maths age of four years. After the intervention, they had all made an improvement. Ali's and Rami's maths age increased by one year, while Hani's maths age increased by nine months.

Table 5. 3 TEMA-3 test results pre- and post- TEN-DD intervention

Child	**Raw score**		**Math ability score**		**Age equivalent (in months)**	
	Pre-test	**Post-test**	**Pre-test**	**Post-test**	**Pre-test**	**Post-test**
Ali	16	22	90	97	54	63
Hani	1	6	55	61	<36	45
Rami	9	20	71	89	48	60

Mothers' Experiences of the Intervention

After the eight weeks of the study, all three mothers were interviewed informally about their experiences. These interviews were not recorded or transcribed, but notes were taken. Mothers' names are pseudonyms.

Delivery of the training.

All the mothers indicated that they were satisfied with the training. Nadia commented that: 'the training was well delivered and structured'. Nura stated that the training was clear and provided pertinent information: 'I understood what I will do, and how'. They also found the practical element of the training beneficial. All of the mothers expressed the view that the roleplay exercises during training helped them know how to use the intervention in practice: 'It was very helpful when we practised delivering targets - when I was acting as a child and the other mum as the mother's child' (Laila).

There were some suggestions for how to improve the training. Nadia suggested that the training should be longer than the three hours provided, as she felt that there was too much information to deliver in the shorter session. She also advised that it would be helpful to have video examples of a teacher working with a child in addition to the roleplay exercises: ‘It would be helpful if there was a video of a mother or teacher, and a child showing how to deliver targets’. She added that ‘having this video would help by referring to it during the implementation’. Laila also suggested that follow-up training in addition to the initial workshop would have been beneficial: ‘I would have liked some follow-up training, maybe midway through the eight weeks’. Similarly, Nura suggested that ‘have the first training session and then do one-week trial, after that have another training session to ask questions and discuss any difficulties we face’.

Implementation of TEN-DD.

The mothers reported positive experiences about the intervention implementation. Laila commented, ‘it’s gone very well, it’s a successful programme’. Nura stated, ‘it’s a good programme to do with my child’. All mothers reported that initially they were not sure about which teaching targets they should start with (it was required that mothers should deliver three targets from the first three key topics of the Emergent stage: one target from each key topic). The telephone consultations though did help to clarify where to start teaching: ‘At first, I was not sure where should I start and what target should I introduce to him, but when you phoned me you explained to me and then I was fine’ (Nadia). The mothers also reported that they liked using a token board with their children: ‘I like having the token board - it helped in keeping my child attending sessions till the end’ (Laila). In addition, mothers also explained how their children enjoyed participating in the teaching sessions. Nura reported, ‘my child liked the work’. Laila explained, ‘he brings me the resources box and asks (me) to teach him’. Nadia said, ‘my child quickly gets used to it’.

Mothers reported a few challenging aspects of using the intervention with the children. Although Laila explained, ‘I struggled with teaching my child how to count backwards and count from any given number - he found it hard’, she went to say, ‘but you provided me some ideas to do and it worked well’. Data collection was difficult for Nura ‘I found tracking my child’s progress a bit hard - I actually can’t think of a way you could change it, but it would be helpful if you make it easier’.

The mothers were complimentary about the teaching materials provided for the intervention. Nadia explained: ‘The materials are very well organised’. Nura stated: ‘the laminated resources are appropriate for what I am delivering’. Laila, who required the Arabic version of the teaching plans, reported the benefits of this: ‘I have very little English, so I used (the) Arabic version. I was happy that everything was in Arabic and clear’.

Perceived impact.

The mothers also talked about the beneficial outcomes for their children as a result of using the numeracy intervention. All mothers reported that their child’s numeracy skills had improved. For example, Nura explained: ‘he made very good progress-his maths’ skills improved’. Laila stated: ‘now he can count backwards and count from any given number’. The mothers also talked about collateral benefits of the intervention too. For example, the mothers believed that the intervention had a positive impact on their children’s ability to sit working at a table, and improved their concentration: ‘I noticed that he can concentrate more and sit down for more time’ (Nadia). Nura also reported perceived benefits of the intervention for her child’s speech:

‘I found that my child’s speech really improved’. The mothers commented too about the generalisation of numeracy skills to different situations and settings that had been taught in the structured teaching sessions. Nadia reported: ‘he keeps counting objects that he uses or sees’. Nura stated: ‘last week, when we went shopping, he counted tins of beans and I asked him, ‘How many altogether?’ He answered correctly’. Laila mentioned that ‘he liked counting page numbers of his favourite story book and his toy cars’.

The mothers also indicated that implementing the intervention had a positive impact on their knowledge of teaching numeracy skills to their children. For example, Nadia explained: ‘I learned how to teach maths. I don’t have any experience of teaching maths. I always struggle teaching him’. Nura reported that ‘now I have the ability to sit down with him and do activities for long time’. In addition, learning about prompting and prompt fading was mentioned by Laila: ‘I learned how to provide him strategies of help when needed and how to reduce this help’. Interestingly, Nura said that ‘I used some of targets with my youngest typically developing son, and it worked well’.

The mothers recognised the potential of the intervention and wanted to continue delivering it to their children: ‘I will keep delivering more sessions - so my child could progress quickly. Also it would be great if I could have the next stage of the intervention’ (Laila).

Views about support received.

Support received in the telephone sessions provided during the intervention implementation was praised. For example, Nura mentioned that ‘I will not be able to do it without your help-you put me on track’, and Laila stated that ‘I always asked questions, you provided me helpful ideas and it worked well’. Nura also mentioned that ‘it was helpful discussing some examples of doing generalisation; you always remind me of doing generalisation'. Having one telephone session every week during the eight-week period was reported as enough. However, Nura said that 'it might be helpful if there was a home visit in the middle of the eight weeks so you could model with child in front of the mum. But in general, I really benefited from the telephone sessions'.

Conclusions

The current study showed that it is possible to adapt the TEN-DD numeracy intervention for a home context and to teach mothers to deliver TEN-DD to children with ASD. In addition, with some support from an expert in the intervention, encouraging outcomes were obtained from the short eight weeks of intervention. Mothers also valued the training, the support, and the intervention. We also successfully adapted and translated the intervention from English into Arabic, providing preliminary evidence that TEN-DD might be adapted for delivery in additional contexts internationally.

However, the main focus of this study was to explore whether the TEN-DD numeracy intervention could be delivered in the family context and potentially in Arabic. It is crucial to explore the perceptions of the mothers about the TEN-DD, since these may affect uptake of interventions in practice. Such perceptions also represent 'social validity': that the methods used to teach children with ASD mathematics skills are considered appropriate by parents. According to Wolf (1978), the social importance of an intervention should be evaluated by determining the social appropriateness of intervention procedures and examining the social importance of intervention outcomes. These judgments, when made by stakeholders regarding an intervention, reveal whether or not an intervention is viewed as important; and as a consequence, indicate whether or not the intervention is socially valid. Therefore, the mothers were interviewed informally to obtain their experiences about TEN-DD. It should be noted that a qualitative analysis of interview data from the mothers was not completed. However, data obtained from the mothers provided an initial insight into the perceptions and experiences of parents of children with ASD on the TEN-DD intervention which in turn could inform future research. On the other hand, findings from the informal interviews with the mothers might be different if a qualitative analysis was conducted. Indeed, conducting a qualitative analysis of interview data from the special educators (Chapter 4) shows the value of these sorts of data collection methods, by obtaining an in-depth view of special educators' experiences about the TEN-DD intervention. Therefore, conducting a qualitative analysis of interview data from the mothers would provide a more complete understanding of the mothers' experiences about the TEN-DD intervention. However, the informal interviews covered the domains that mentioned by Wolf (1978) when evaluating the social validity of an intervention.

Given the positive outcomes from this initial evaluation, more robust research is needed to test the effectiveness of parent-mediated TEN-DD to teach numeracy skills at home to children with ASD and other educational needs. In addition, we only examined the Emergent stage curriculum in the current project, and additional research should examine using the whole TEN-DD curriculum and how best to sustain support for parents over a much longer period of intervention.

Chapter 6: General Discussion

The field of ASD in the Arab context is relatively young. ASD in Arab countries is not yet a priority, with very few research studies and limited services. This thesis has attempted to expand our knowledge of the state of children with ASD in the context of Arab countries and cultures. As a part of that broad aim, the research also contributed to research evidence in the UK context that would assist future work in an Arab context.

Accordingly, we systematically reviewed previous research conducted on individuals with ASD and their family members in Arab countries and cultures (Chapter 2). Following this, three studies were carried out (Chapters 3, 4, 5) which explored both support needs and educational intervention. In the current chapter, I will summarise the findings of the empirical work conducted within this thesis, discuss the implications of the thesis as a whole, and limitations and future research directions.

Summary of Thesis Findings

It is somewhat surprising how little research attention has been given to ASD in Arab countries and cultures. In Chapter 2, a review of the extant literature on social, educational, and psychological research focused on individuals with ASD and their family members in Arab countries and cultures was presented. Systematic searches were conducted including eight electronic databases, hand searches of reference lists and citations of all included studies, and other reviews on the topic. Seventy studies were included in the review: 23 studies examined prevalence of ASD and diagnosis issues, 37 studies examined experiences and outcomes for Arab caregivers of individuals with ASD, and ten studies examined social and communication behaviour of Arab individuals. Most of the identified studies were conducted in three countries, that is, Jordan, Saudi Arabia, and Lebanon. Additionally, most of these studies (50%) were carried out more recently (between 2012 and 2017). A small number of studies (12) were conducted in non-Arab countries but with Arab populations. None of the 70 studies identified were published in Arabic. Out of the 70 studies, 59 were quantitative studies, seven were qualitative studies, one single case experimental design study, and three case studies. Cross-sectional designs predominated. Questionnaires were the most common data collection method, while few studies used personal interviews or telephone interviews. The most targeted populations in the 70 studies were families (parents or caregivers) (54%), followed by children with ASD (43%) and adults with ASD (3%). There were significant gaps in the research evidence base. Research on interventions, particularly educational interventions, was scarce. Further, there were few data on ASD services in terms of their organisation, effectiveness, or consumer perspectives. Overall, the included studies were appraised as being of weak quality.

Chapter 3 investigated an area thus far unexplored within the literature, that of the support needs of Arab families of children with ASD living in the UK. The study also examined psychological distress and parental relationships (parental relationship satisfaction and parental disagreement over issues related to the child with ASD) of Arab parents of children with ASD living in the UK, and identified child and parent factors that predict support needs, psychological distress and parental relationships. The analyses showed that Arab parents of children with ASD in the UK reported the highest need for information, community services, and explaining to others. In particular, the most commonly reported needs were for information about services for the child, both now and in the future; information regarding how to teach and handle the child's behaviour; meeting and talking with other parents who have a child with ASD; locating a dentist for the child; and finding reading material about other families who have a child with ASD. High levels of psychological distress were found in the parents. In addition, the majority of the parents reported high levels of relationship satisfaction with their spouse or partner and, no disagreement with their spouse over issues related to the child with ASD. This exploratory study found that higher levels of child behaviour problems were associated with increased family needs. The child's prosocial behaviour, parent's health status and number of children in the family were found to be negative predictors of parental psychological distress levels. The study also found that the longer families had been in the UK, the more parental disagreement over issues related to the child with ASD was reported. This study has made a distinct contribution to the literature by providing greater understanding of support needs, psychological distress, and parental relationships of Arab families of children with ASD living in the UK.

The research described in Chapter 4 is unique in that it explored the experiences and perceptions of special educators from a special school, of a structured numeracy intervention used with their pupils with ASD. The research was carried out as part of a series of steps to develop evidence around a numeracy intervention that may in future contribute to the education of children with ASD in Arab countries. The reported study also made a wider contribution to the international literature, as it is the first qualitative study in the field to have captured the experiences of educators in the autism department in of a special school around the use of the TEN-DD numeracy intervention in the classroom. Analysis of the interview data indicated that taking part in the numeracy intervention was a valuable experience for both the educators and their pupils. There was an initial scepticism about the intervention, but this changed to conviction during the implementation period. Educators reported an increased sense of competence in their teaching skills, which was evident in reported greater satisfaction and increased self-efficacy. Furthermore, there was a strong interest in continuing to use the numeracy intervention with pupils.

Chapter 5 of this thesis has made a distinct contribution to the literature not only in the ASD field generally, but also specifically in the Arab context, by being the first study to have carried out any evaluation of the TEN-DD numeracy intervention in a home context and with Arab families in the UK. The TEN-DD intervention was evaluated with three children with ASD, by training and supporting their parents to deliver the intervention over the course of an eight weeks intervention. Using pre-test post-test design, outcomes from a standardised assessment demonstrated that the three children's mathematical ability improved over the course of the intervention. Parents also reported positive experiences of their training and of using the intervention, especially mentioning how much their children had progressed in their understanding of mathematics.

Contribution of the Thesis

This thesis is unique and has made a great contribution to the field of ASD, in particular children with ASD and their families. Indeed, to the best of the researcher's knowledge, this thesis is the first of its type in the area of ASD, not only in the context of Arab countries and cultures but also in the UK context. Thus, it will help to develop a comprehensive understanding of the current state of research on children with ASD and their families.

This thesis explores neglected areas of ASD research, including experiences of raising a child with ASD in the Arab context and academic intervention. The thesis provides information on support needs, psychological distress, and parental relationships of Arab parents of children with ASD living in the UK. This information will help to better understand those parents and find ways to support them effectively, which in turn can benefit their children with ASD and their family as a whole, especially their mental health. Indeed, previous research suggested that social support may assist to reduce the negative outcomes associated with raising a child with an ASD (Bromley, Hare, Davison, & Emerson, 2004; Hassall, Rose, & McDonald, 2005).

Further, this thesis has the potential to provide insights into academic intervention in the Arab context, in particular mathematics intervention. The systematic review demonstrated that there is a paucity of implementing academic interventions in the Arab context. Thus, translating and evaluating the numeracy intervention in the Arab context will support the state of ASD education and provide strong evidence to special educators, parents, and other stakeholders involved with teaching numeracy to children with ASD. Findings from this research could encourage ASD researchers in the Arab world to investigate whether the numeracy intervention can be adapted and delivered in the education system of an Arab country. In addition, this research shows that it is possible to adapt existing interventions for the Arab context, which in turn may encourage other researchers in the Arab world to adapt and implement existing academic interventions. Further, this thesis qualitatively explored special educators' perspectives of the numeracy intervention use for children with ASD in a special school setting. This exploration provides in-depth information that can support further planning for the numeracy intervention for children with ASD. Moreover, this exploration provides a basis for future research using qualitative approaches to explore special educators' experiences of an intervention in the Arab context.

In addition, researchers in non-Arab countries such as the UK, where many of Arab families of children with ASD live, are uninformed about the perspectives of ASD in the Arab context. Thus, this thesis may help to create a critical level of awareness, which may in turn stimulate more research in the field of ASD in that context.

Moreover, since most of the research in the area of ASD has been conducted in Western countries, it is useful to bring in different perspectives from different cultures, which helps to improve the overall knowledge about children with ASD and their families.

Implications for Practice

The findings from the four empirical chapters of this thesis have a number of implications for practice. First, Chapter 2 clearly showed the poor evidence base for interventions for individuals with ASD and their families in Arab countries and cultures. In particular, educational interventions were scarce. Thus, it is clear that it is important to use evidence of interventions from non-Arab countries. Adapting existing evidence-based interventions for Arab cultures is a continued need. The implementation of evidence-based interventions across cultures will need some degree of adaptation (Doyle & Hungerford, 2014). Adaptation is a process that aims to tailor an existing evidence-based intervention to meet the different needs or desires of a new context in which it is to be utilised, and not to invent an entirely new intervention (Card, Solomon, Cunningham, 2011; Chen, Reid, Parker, & Pillemer, 2013). Adaptation of an intervention can be made to the procedure, for example time, location, recruitment, delivery, staff; dosage, e.g., number or length of lessons or sessions; content, e.g., adding or removing lessons; participants, e.g., targeting a different population; or cultural relevance, e.g., making the programme suitable for the current group (Moore, Bumbarger, & Cooper, 2013). According to Jani, Ortiz, and Aranda (2009) interventions are more successful when they are culturally adapted, as this assures a good fit. Cultural adaptation may consist of accommodation of language differences, modifications made to allow ‘fit’ where professional practices might be different, or change to the intervention itself (Bernal, Jimenez-Chafey, & Domenech Rodrıguez, 2009; Whaley & Davis, 2007).

Cultural adaptation has been shown to enhance the pertinence, acceptability, effectiveness, and sustainability of interventions for both providers and target population, without having negative effects on findings (Baumann et al. 2015; Kumpfer, Alvarado, Smith, & Bellamy, 2002). For example, a parent-training intervention (Parent-Child Interaction Therapy) developed for parents of children with behavioural problems was adapted for Puerto Rican parents of young children with hyperactivity and other significant behaviour problems. Prior to this adaptation, the intervention had mainly been studied with Caucasian English-speaking families in the United States. The adaptation process contained the following steps: translation and preliminary adaptation of the intervention manual; conducting an initial exploratory study of the adapted intervention; adaptation revision and refinement based on parents' suggestions; in-depth interviews with parents who completed the intervention and clinical psychologists who checked the adapted intervention manual for any cultural barriers; conducting a pilot randomised controlled trail which found that parents benefited from the adapted intervention (Matos, Torres, Santiago, Jurado, & Rodriguez, 2006). Chapter 5 has shown that it is possible to adapt an existing educational intervention, the TEN-DD numeracy intervention, for the Arab family context, and potentially keep the successful outcomes of the original intervention. However, it must be conceded that ours was a small-scale study and did not include a control group. Researchers and practitioners within the UK should keep in mind the importance of cultural adaptation of existing intervention tools that could be used with Arab children with ASD and their families.

Secondly, providing an initial insight into support needs, psychological distress, and parental relationships of Arab families of children with ASD living in the UK is a critical first step towards enhancing components of service delivery, providing interventions and subsequently improving Arab parents’ mental health and family outcomes. The findings from this study could inform professionals, funders, service providers, and policy makers in tailoring services to best meet Arab family needs. In addition, our newly translated Arabic measures can be used by other disability researchers, both in Arab countries and in non-Arab countries (e.g., UK, to conduct research on assessing Arab family needs). Further, this study can be replicated in the Arab world, as survey research of this sort on the needs of Arab families of children with ASD is wholly absent. In particular, findings from the study indicated that there is a continued need to provide support groups to the Arab families in the UK, as they have reported a need to acquire information about current and future services for their children with ASD, and the need for meeting and talking with other parents who have a child with ASD. These kinds of needs might be imparted efficiently by providing parent support groups.

According to Rawlins and Horner (1988), parent support groups are designed to provide mutual support and friendship and to collect and disseminate information regarding the prevalent disability. Meeting other parents of children with ASD in support groups can benefit parents by providing them a place to discuss their obstacles, to share advice, experiences, coping strategies, and restore parental confidence (Luther, Canham, & Cureton, 2005; Papageorgiou & Kalyva, 2010). Talking with other parents who encounter the same stressful caretaking responsibilities may provide parents with a broadened view on what information and services are available (Koroloff & Friesen, 1991). Additionally, siblings of the child with ASD and extended family members who involve in childcare duties can take advantages from support groups (Luther et al., 2005). Papageorgiou and Kalyva (2010) found that the main reasons that encourage parents to participate in support groups included: being informed about the new developments in the field of ASD, receiving practical support, meeting and talking with other parents, and gaining from counselling. In addition to parent support groups, accessing social media fora might help Arab parents of children with ASD to obtain tips on issues related to their children with ASD. Moreover, professionals and practitioners within the UK who work with Arab families of children with ASD could cooperate together to establish a reliable information dissemination platform to guide those families.

There was also emerging evidence from the findings that professionals need to direct attention to the design and delivery of effective educational and behavioural interventions with Arab parents of children with ASD, as parents reported the need for information on how to teach and handle their children's behaviour. From this study, there is also a clear need for providing psychological support to the families, as high levels of psychological distress were found in the parents. Therefore, UK professionals and practitioners who interact with these families need to be sensitive to the mental health of these parents and should focus on helping the family cope with their child. It should be highlighted that high levels of psychological distress among the parents might be related to the acculturation process. As mentioned in Chapter 1, Arab migrants who live in the UK may require a degree of acculturation by adopting the practices, values, and identification of the UK. Alegría et al.(2008) found that greater degrees of acculturation were associated with problematic health outcomes, in particular assimilation is associated with negative health outcomes. Therefore, Arab parents of children with ASD who live in the UK may be particulary impacted by accultrative stress (Schwartz et al., 2010) in addition to raising a child with ASD. Further attention should be directed to the importance of acculturation process among Arab families of children with ASD who live in the UK.

Parents of children with ASD are anticipated to be in vital need of adopting effective coping strategies to manage their children's lifelong disability (Dardas & Ahmad, 2015a). Recent research has highlighted the considerable role of coping strategies as influencing stress and mental health in parents of children with ASD (e.g., Benson, 2010; Hastings et al., 2005a; Hastings et al., 2005b; Paynter, Riley, Beamish, Davies & Milford, 2013; Stuart & McGrew, 2009). Coping refers to how an individual responds cognitively, behaviourally, and emotionally to deal with the demand imposed by a stressful situation (Lazarus & Folkman, 1984). Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986) found that the process of coping can change the relationship between life stressors and health. In general, ineffective coping strategies can form negative emotions, harmful long-term impacts, and needs for additional and/or different coping efforts, while, effective coping strategies lead to positive emotions and beneficial long-term impacts (Lazarus & Folkman, 1984).

Based on the Stress and Coping Model of Lazarus and Folkman (1984), research has generally distinguished between problem-focused and emotion-focused coping strategies. Problem-based coping involves strategies that focus on solving or changing the problem or stressor; on the other hand, emotion-based coping strategies aim to decrease or manage the feelings of psychological distress connected with the stressor. Understanding a parent’s coping strategies may assist a better understanding of how parents respond to the stresses of caring for a child with ASD (Pepperell et al., 2018). Research in ASD demonstrated that fathers more often use problem-focused coping strategies such as planning or task-focused reactions, meanwhile mothers tend to engage in emotion-focused strategies including denial, avoidance, or venting (Borden & Berlin, 1990; Lutzky & Knight, 1994; Seltzer, Greenberg, & Krauss, 1995). Emotion-focused strategies were found to be associated with higher levels of psychological distress and poorer mental health outcomes than problem-focused strategies, thus researchers have argued that this might simply explain why mothers often have higher psycho-social difficulties than fathers (Abbeduto et al., 2004; Hastings et al., 2005a; Seltzer et al., 1995). Thus, practitioners within the UK should target the design and delivery of interventions that enhance problem-focused coping in Arab parents of children with ASD.

Arab parents, especially mothers, would benefit from providing counselling services and attending parent support groups to develop effective coping strategies in order to experience satisfactory levels of mental health and well-being. Further, Arab parents can learn effective coping strategies through participating in some intervention programmes. For example, it has been found that mindfulness-based intervention may alleviate stress and improve health outcomes of parents of children with ASD (Ferraioli & Harris, 2013). Mindfulness boosts decentering after appraisal of a circumstance as stressful, which leads to a state of widened attention from which individuals can then more easily reappraise their life circumstances, and provides them with a new advantageous or positive meaning (Garland, 2007). The benefits of mindfulness-based interventions have been documented in Arab, in particular Jordanian, parents of children with ASD (Chapter 2) for improving quality of life including psychological and social health domains, and positive stress reappraisal (Rayan & Ahmad, 2016). Thus, it would be culturally appropriate to provide mindfulness-based interventions to Arab parents of children with ASD living in the UK.

Lazarus and Folkman (1984) suggested that an individual's internalized cultural values, beliefs, and norms impact the appraisal process of stressors and the perceived appropriateness of coping responses. Stress and coping are arithmetric worldwide experiences encountered by individuals regardless of culture, ethnicity, and race, but members of different cultures might consider and respond to stressors differently with respect to coping goals, strategies, and outcomes (Chun, Moos, & Cronkite, 2006; Lam & Zane, 2004). Culture is one of the fundamental aspects of society that impacts both the person and the environment (Chun, Moos, & Cronkite, 2006). Culture is best defined as a highly complex, continually changing system of meaning that is learned, shared, transmitted and altered from one generation to another (Triandis, 1995). This system of meaning includes the norms, beliefs, and values that provide prescriptions for behavior (Chun et al, 2006). According to Wong and Ujimoto (1998) culture impacts the stress-coping process by: (a) determining what is stressful, (b) predisposing individuals to respond to stress in a customary approach, (c) defining the nature and the range of resources used, (d) affording cultural knowledge for culturally suitable coping responses in view of a given stressor, and (e) dictating the manifestation of coping consequences.

Kuo (2011) systematically reviewed research conducted on cultural differences and specificities in coping patterns across national, ethnic, and racial groups. In a study by McCarty et al. (1999) Thai children (age 6 to 14) were twice as likely to report using 'covert' emotion-focused coping strategies than did American children when they faced powerful adults, such as in the scenarios of receiving a doctor's injection and encountering angered parents or teachers. The researchers noted that the prevalent use of covert coping in public among Thai children may represent Thai culture's emphasis on interdependence, social harmony, and respect for authorities (McCarty et al. 1999).

Evidence of differential cultural coping patterns is further substantiated by ethnic and racial comparative coping research. Bjorck, Cuthbertson, Thurman, and Lee (2001) found that Korean and Filipino American church attendees reported more passive or emotion-focused coping and higher scores on all coping scales than their Caucasian American counterparts. However, Filipinos also endorsed more problem-solving coping than did Caucasians. The flexible use of both emotion- and problem-focused coping by Filipino Americans was said to be prompted by the heightened stresses associated with their minority status in the United States.

Furthermore, in a study by Chiang, Hunter, and Yeh (2004), both African American and Latino American college students identified family and religion to be highly important sources of help and coping for them in dealing with personal, interpersonal, and academic stressors. However, turning to parents was more important for Latino Americans while engaging in religious activities was more important for African Americans. The authors explained that the coping preference of African Americans reflected the centrality of spiritualism and religion in Afrocentric values. Indeed, religiosity or spirituality may be an important personal factor influencing appraisal by enabling individuals to assess the event in a more positive and purposeful light (Lazarus & Folkman, 1984). McConkey et al (2008) explored the coping strategies utilised among Irish, Taiwanese and Jordanian mothers of children with intellectual disabilities including autism. Results revealed that Jordanian mothers reported greater use of religious coping strategies than their Irish and Taiwanese counterparts. These findings might be explained by the Jordanian culture where one need to believe in God’s will and pray to bring comfort and calm (Dardas, 2014). In addition, seeking social support was found to be the highest coping strategy in used among Arab parents of children with ASD (Dardas, 2014). Social support is considered a valued Arabic tradition that plays a prophylactic role in the development of mental health problems. The extended family in the traditional Arab culture was found to significantly help individuals deal with their life stressors (El-Islam, 2008).

Thirdly, findings from Chapter 4 support previous research outcomes regarding the importance of systematic instruction when teaching mathematical skills to children with ASD (Dunlap, Iovannone, & Kincaid, 2008). Indeed, it was noted that systematic instruction was the general procedure associated with the best outcomes when teaching academic skills to children with developmental disabilities (e.g., Browder, Ahlgrim-Delzell, Spooner, Mims, & Baker, 2009; Spooner, Knight, Browder, Jimenez, & DiBiase, 2011). The TEN-DD intervention is based on systematic instruction which consists of identified and measurable targets, systematic utilisation of prompting and prompt-fading procedures, generalisation steps, and data collection in every session (Tzanakaki et al., 2014b). Furthermore, a qualitative investigation into the experiences of special educators in an autism department in a special school around the use of the TEN-DD intervention in the classroom, provided rich data which may aid informed decision making by administrators and other key stakeholders regarding programme intervention. The study filled an evident void in the area of social validity of the TEN-DD numeracy intervention. Using qualitative methodology helped to expand our knowledge about how TEN-DD works, how participants feel, and what factors might impact the success. Also, we have found that special educators' experiences when using the TEN-DD numeracy intervention are in line with previous research (e.g., Willey, Holliday, & Martland, 2007). Teachers and teaching assistants reported that their knowledge, understanding and practice of numeracy teaching developed significantly by using the related Maths Recovery curriculum with their typically developing pupils who were below age-related expectations for numeracy skills (Willey et al., 2007).

Interestingly, educators in Willey's study and our study reported a rise in their expectations raise of what children can learn and achieve.

In addition, it was evident that teaching assistants (TAs) can effectively deliver the TEN-DD intervention to pupils with ASD, thereby strengthening their role in special schools; this can be advantageous for children with disabilities. Indeed, previous research demonstrated that paraprofessionals (TAs) can provide support for pupils with disabilities that enhances academic skills. Providing explicit training to TAs on teaching strategies can improve the effectiveness of their involvement in special education, which in turn could benefit pupils with disabilities (Browder, Wood, Thompson, & Ribuffo, 2014). For example, McDonnell, Johnson, Polychronis, and Risen (2002) demonstrated the effectiveness of embedded instruction delivered by paraprofessionals. Paraprofessionals successfully taught vocabulary word and definition identification to four pupils with moderate intellectual disabilities. Findings revealed that the pupils were able to obtain and maintain literacy skills.

Fourthly, as found in Chapter 2, it was evident that there is a clear need for exploring effective strategies of interventions, especially educational interventions. In Chapter 3 Arab parents reported the need for information on how to teach their children with ASD. Therefore, evaluating the TEN-DD numeracy intervention in the Arab context, provided initial evidence on methods to support educational interventions. There is little known about how parents of children with ASD make decisions regarding which interventions to utilise with their children. It is argued that parents' beliefs about child development, interpretation of the symptoms of ASD, and its aetiology affect intervention decisions (Mandell & Novak, 2005). Indeed, Alqahtani (2012) found that Saudi parents of children with ASD believed that the cause of ASD is attributed to medical reasons such as examination during pregnancy, vaccination, and vitamin deficiency, as well as cultural reasons like the evil eye and black magic (Alqahtani, 2012). Therefore, the most common interventions used by Saudi parents of children with ASD were medical, cultural, and other informal interventions such as reading the Quran, or asking for help from religious healers (Sulaimani, 2018; Alqahtani, 2012). Alqahtani (2012) argued that such interventions are desirable as they are perceived as curing the cause of symptoms rather than the symptoms themselves. Interestingly, no parents mentioned using basic therapies focusing on behavioural, educational or developmental interventions. Thus, there is a need to examine and potentially provide appropriate multidisciplinary interventions consisting of behavioural and educational interventions to children with ASD and their parents (Alqahtani, 2012). However, Alqahtani (2012) stressed that professionals should be aware of and sensitive to parents' different beliefs regarding ASD. Consequently, there is an important need to explore what Arab parents of children with ASD think about interventions, and how they make decisions regarding which interventions to implement with their children.

With the increase of cultural diversity in populations, researchers encounter with new issues, such as dealing with participants from other cultures who speak different languages. Participants who live in countries or regions other than where they were born. This has had an influence on many features of our life. In the scientific world, one influence that has been found is the need to translate research tools for use with people speaking different languages (Banville, Desrosiers, & Genet-Volet, 2000). Thus, providing a translated version in the Arabic language of the TEN-DD numeracy intervention, even if only the first stage of the intervention so far, can be beneficial for researchers, interventionists, parents and children with ASD and other developmental disabilities who are of Arab background.

As outlined in Chapter 1, cultural similarity and language may determine which subgroups of migrants may encounter different types or degrees of acculturative challenges. Indeed, individuals who cannot speak the language of the country or region in which they are settling may experience a greater degree of acculturative challenge (Schwartz, et al., 2006, Schwartz et al., 2010). Thus, Arab parents of children with ASD who cannot speak the language of the UK might be less likely to receive appropriate intervention services. Providing an Arabic version of the TEN-DD intervention to the mother who had very little of English was beneficial and accomodated a potential acculturation issue that related to language. Language is an important factor that should be considered by researchers and practitioners within the UK who interact with Arab families of children with ASD.

I have found that it is possible to translate an intervention from English into Arabic. However, Caro and Stiles (1997) indicated that "translating is not a simple mechanical matter of changing words from one language to another one but a subtle and personal task, an act of re-creation of reconstruction" (p. 233). From my own experience of translating the intervention and questionnaires (Chapter 3), translating the TEN-DD intervention was easier than the questionnaires. This might be due to the focus of the TEN-DD intervention which involves numbers, repeated terminologies, and easy instructions. Arabic is a single written language but has many spoken dialects, and many different regional variants of some words can be found (Arabiat, Elliott, Draper, & Al Jabery, 2011). Therefore, translating an intervention manual for a different curriculum area, for example a science curriculum, might be more difficult.

In addition, results from this study build upon previous research studies (Tzanakaki et al., 2014a, Tzanakaki et al., 2014b), as it showed that using the TEN-DD numeracy intervention for children with ASD is potentially beneficial, as a positive attainment in numeracy skills was still made. The results achieved by children and mothers in a short space of time, with limited training and support, were very promising. Accordingly, this emerging evidence could encourage governmental agencies, special schools and centres to further examine the TEN-DD numeracy intervention when teaching children with ASD. Results from this study could also inform non-governmental organisations' decisions in allocating funds to disseminating such interventions. Moreover, the mothers who engaged in the implementation of the numeracy intervention reported positive experiences about the intervention implementation. They developed an enhanced faith in their children to learn and understand numeracy. Alongside this, they became more confident in their own ability to teach numeracy to their children. Thus, this study provided a basis for further research using the TEN-DD numeracy intervention to teach children with ASD in the home context.

In addition, we have found that the mothers were highly interested in our investigation of the TEN-DD intervention and willing to cooperate with us over the project by offering a place to deliver the training, recording data, commitment to telephone support sessions, and having a short discussion with us at the end of implementing the intervention to explore their experiences. All of these factors may contribute to the success of implementing the intervention in the Jordanian context, with children with ASD using their parents as mediators. However, in Jordan, children with ASD are educated in public and private centres with or without residential services. The special education system is mainly focused on helping children to live independently by teaching them daily life skills, self-care, basic academic skills, and making some handcrafts (Abu-Hamour & Al-Hmouz, 2014). Historically, education in Jordan has been considered as the responsibility of the schools. Parents’ involvement with their children’s education is considered as interference with what specialists are supposed to do (Abu-Hamour & Al-Hmouz, 2014). Thus, using Jordanian parents as mediators of the TEN-DD intervention might not be feasible. In addition to this, as mentioned previously (Chapter 1), in the Arab culture disability is associated with social stigma (Crabtree, 2007; Dababnah & Bulson, 2015; Nazzal & AL-Rawajfah, 2018; Sulaimani, 2018). Alqahtani (2012) demonstrated that mothers hesitate to ask for help for their autistic children due to their fear of the cultural stigma associated with disabilities. Therefore, Jordanian parents of children with ASD might not be willing to take part in a research project, perhaps because a child’s disability is too personal an issue for discussion with outsiders (Abu-Hamour & Al-Hmouz, 2014).

Given these cultural considerations, implementing the TEN-DD intervention in the Jordanian context might be more likely through the special education system. In Jordan, special educators are trained to be qualified to teach pupils with special needs including ASD. There are undergraduate and graduate programmes in special education offered by universities in Jordan for many years. Special education programmes offer training on different types of disability (Abu-Hamour & Al-Hmouz, 2014). Indeed, Al Jabery et al. (2014) found that Jordanian parents of children with ASD were satisfied with special educators’ professional and personal characteristics including commitment, knowledge about ASD, their ability to handle the child’s behaviour, and their understanding of the child’s problems. Thus, these indications may suggest the availability of suitable educators to be trained in the TEN-DD intervention. Although the translated Arabic version of the first phase of the TEN-DD curriculum (known as Emergent) was checked by an Arabic-English bilingual individual who was experienced in teaching mathematics in Jordan, further consideration needs to be given to see if the tranlsation would be appropriate for the school context. For example, the generalisation sections could be translated, as mentioned in the original (school-based) TEN-DD curriculum.

Lastly, it is clear that research included in this thesis did not involve co-construction with people with ASD and their families. Thus, greater attention should be turned to the importance of involving people with ASD and their families in research about them in the context of Arab countries and cultures. It is well recognised that the vast majority of ASD research is still conducted on people with ASD rather than with them (Chown et al., 2017). People with ASD and their families are rarely involved in the decision-making processes that direct research and its application (Pellicano, Dinsmore & Charman, 2014). It has been argued that it is epistemologically and ethically problematic when the autistic voice is not heard regarding social scientific research that aims to further improve knowledge of autism (Milton & Bracher, 2013). The involvement of different autistic voices in autism research is not merely as sources of empirical material or objects of inspection, but as active partners in the creation of knowledge on autism (Milton & Bracher, 2013). Accordingly, the movement of autistic self-advocates in research has emerged, for instance the Autistic Self Advocacy Network, ASAN. People with autism reported that “we know what we need, what our lives are like, and what will help. Autism researchers should work with autistic people, so we can tell them what we need and what would help us. This will make the studies better” (Autistic Self Advocacy Network’s Community Living Summit: what autism researchers should study, 2018 p. 3). Indeed, Milton and Bracher (2013) indicated that the inclusion of autistic people as equal participants can assist in enhancing the research process in which the research agenda would be widened, rapport with research participants might develop, distribution of outcomes would be less offensive to the autistic society, and autistic people would be less alienated from knowledge created in the area. In addition, Zuber and Webber (2019) mentioned that including people with ASD in the educational discussions and research about them helps to attain academic purposes, independent living, enhance confidence and employment outcomes. For example, Barnard-Brak and Fearon (2012) stressed the significance of self-advocacy of autistic pupils and their involvement in developing their individualised education programmes.

In Chapter 2 there were no studies conducted with individuals with ASD and/or their families as co-researchers or using co-production. In the context of Arab countries and cultures it might be challenging to involve people with ASD and their families in research about them. Indeed, people with ASD and their families face social stigma and discrimination (Nazzal & AL-Rawajfah, 2018). Social stigma has been identified as a mark of social disgrace in which the targeted person is discredited based on attributes such as ethnicity, mental health problems or disability (Goffman, 1963). The construct of stigma refers to attitudes, stereotypes, prejudice, and discrimination (Corrigan, Roe, & Tsang, 2011), which result from misconceptions about a person’s attributes by the dominant cultural group, and are perpetuated through biased social structures (Corrigan, 2000). According to Crabtree and Nagata (2007) social stigma still prevail in Arab societies where people with disabilities including ASD are shown as a heavy burden on families, caregivers, and society in general. Indeed, Palestinian parents of children with ASD hesitate seeking professional help due to the fear of stigma associated with disabilities (Dababnah & Parish, 2013). In addition, there is a lack of awareness about autism among Arab communities (Zaki & Moawad, 2016). For example, Arab people with ASD and their families do not have the awareness of their rights of being involved in educational decisions (Sartawi & Smadi, 1997; Yousef & Hadidi, 1992). Therefore, Arab countries must exert much more effort to disseminate autism-related information in the community, dispel misconceptions and non-scientific explanations of ASD, challenge cultural representations of ASD, and promote realistic attitudes (Hadidi & Al Khateeb, 2015). People with ASD and their families in the Arab world need to be involved whenever ASD is discussed. Thus, there is a potential need to build a culture where people with ASD can take on active and meaningful roles in research.

Limitations and Future Research

This thesis has contributed new knowledge to the field of ASD research in the context of Arab countries and cultures; however, there are limitations which need to be discussed. Given the lack of research in all of the areas covered in the four empirical chapters, it is important to say that these analyses are only a starting point, and so further work is required.

The findings from Chapter 2 have contributed to the knowledge base on ASD research in the Arab world, in particular neglected aspects of research including social, educational, and psychological topics. Synthesising the literature helped in identifying which areas of ASD research need to be taken into consideration for future research. Accordingly, findings from this study could be adopted by policy makers and other stakeholders in the field of ASD in the Arab context. Furthermore, findings from the study indicated that there is limited research conducted on individuals with ASD and their family members who live in non-Arab countries. However, none of these studies focused on issues of acculturation. Given that this is an important theoretical and practical construct, acculturation among Arab families of children with ASD in non-Arabic countries should be a priority topic in future research. Moreover, the study demonstrated the importance of improving the research infrastructure for ASD and related research in Arab countries and cultures.

It should be noted that the review omitted examination of other important topics of ASD research including medical research. Much of the ASD research in the Arab region has been concerned with medical topics. For example, Hussein and Taha (2013), Salhia et al. (2014), and Alnemary et al. (2017) reviewed published literature on ASD in the Arab world; they found that the most addressed topic was medical issues including biology of ASD; risk factors such as suboptimal breastfeeding, lead exposure, maternal and paternal age, caesarean section, and prenatal complications; biomarkers for ASD and etiology including genetics etiology, autoimmune conditions, hormonal disturbances, nutritional deficiencies and errors of metabolism, environmental toxins, mitochondrial dysfunction and oxidative stress. There was no indication of the quality of any such medical research, due to the absence of conducting quality assessment of the included studies. However, it was evident that the majority of medical research in the Arab region are case reports, or with very limited sample size (Hussein & Taha, 2013; Salhia et al, 2014). It has been proposed that more research is carried out in the Arab region on medical topics than, for example, educational, psychological or social topics, because medical areas might be more developed (Hussein & Taha, 2013) and might not require as much time and effort (Alnemary et al. 2017).

Additionally, the sample of publications included in the review might not be representative of all ASD research from the Arab region, because it only included English publications, although the inclusion criteria of the review included the Arabic language. The picture of ASD research in the Arab world remains incomplete without reviewing Arabic publications. Thus, future systematic reviews using manual searches are recommended in order to obtain an in-depth insight into Arabic language research that is related to social, educational, and psychological aspects focused on individuals with ASD and/or their family members. Future systematic reviews of Arab literature on ASD should also try to include literature published in the French language, as some parts of the Arab world including Algeria, Morocco, Tunisia, and Mauritania use the French language in many areas of life (Aitsiselmi & Marley, 2008). Further, including only journal publications in the review might possibly under- or over-estimate ASD research, as there are alternative means of disseminating research outcomes including conference papers, meeting abstracts, books, book chapters, and research theses and dissertations.

Our data presented in Chapter 3 provided a cross-sectional picture of Arab families' outcomes including support needs, parental psychological distress, and parental relationships. There is the potential for future work to conduct longitudinal investigations in order to capture how Arab families' outcomes including needs, psychological distress, and parental relationships might change over time and allow for the exploration of casual pathways. It would be valuable to examine Arab families' outcomes across the lifecycle, as the needs, coping strategies, and challenges of parenting a child with ASD change over time, which in turn causes families to shift elements of their experiences including their personal lives, their personal and professional relationships, and their perceptions and expectations of the problem (Gray, 2002; Gray, 2006). Further, future work should look into how the relationship satisfaction of Arab parents of children with ASD evolves over time.

It is well recognised that parents of children with ASD have higher levels of stress. Previous research has found that stress levels increase in parents of individuals with ASD as their supports decrease (Boyd, 2002; Bromley et al., 2004). Future research needs to be conducted to explore what supports may decrease the psychological distress experienced by Arab parents of children with ASD. Further, the majority of our respondents were mothers. Therefore, findings are unlikely to be generalisable to fathers of children diagnosed with ASD. A focus specifically on the perspective of fathers is an important area for future research. It is widely recognised that fathers' perspectives are under-represented, and that mothers are often the primary participants in research studies (Flippin & Crais, 2011; Johnson & Simpson, 2013). Fathers are more difficult to engage in research than mothers (Cassano, Adrian, Veits & Zeman, 2006; Phares, Fields, Kamboukos, & Lopez, 2005). Fathers have been identified by researchers as 'hard to reach' (McConkey, 1994) and the 'peripheral parent' (Herbert & Carpenter, 1994). It has been suggested that fewer fathers engage in research studies about their child due to the exclusion of fathers in matters which are related to their child's needs and provision (Phares, 1992). Additionally, fathers are less present in the lives of their children. Therefore, fathers may feel that they are not the 'best' person to provide information on their child, or their parenting experiences are less important to research (Phares, 1996).

As outlined in Chapter 1, in the traditional Arab family fathers have been assigned the role of breadwinner or provider. Thus, fathers are in fact off-stage, spending most of their time outside the home (Barakat, 1993). Mothers have the primary role of raising children and taking care of the house (Al Harahsheh, 2011). Sulaimani (2018) found that Saudi fathers of children with ASD left the responsibility of taking care of the child to the mother, making her the only caregiver of a child who needs a considerable amount of help. Indeed, previous literature on the experiences and outcomes for Arab parents of children with ASD (e.g., Almansour et al, 2013; Dardas, 2014; Dardas & Ahmad, 2013; Rayan & Ahmad, 2016) showed that very few fathers participated in research studies. However, recently fathers are increasingly becoming engaged in the daily care of their children, shifting from breadwinner to co-parenting roles internationally (Lamb, 2000; Pleck & Masciadrelli, 2004; Williams, 2008). Therefore, it is worthwhile focusing on fathers, as fathers' perspectives and experiences play a pivotal role in the child's, mother's, and whole family's health and well-being (Donaldson et al., 2011).

Additional studies comparing mothers and fathers are also needed, especially mothers and fathers in the same family, to ensure that both perspectives are captured. It is also important to keep in mind that the majority of data in our survey were derived from married parents. More work needs to be conducted on single parents or on parents who are divorced or separated, in order to explore their perspectives. The selected age range of children with ASD, from four years to 15 years and 11 months, was another limitation to the study because it prevents the generalisation of the findings to families of children with ASD who are outside this age range. Thus, the inclusion of parents of older individuals with ASD is needed.

Additionally, the use of self-report survey data means that the findings presented in Chapter 3 could indicate perceptions and not necessarily reality. Findings may be different if researchers use other data collection methods such as interviews alongside survey, and this would provide a more complete understanding of Arab families' outcomes. Using interviews may, for example, help the study gain insight into reasons for high levels of psychological distress among parents despite high levels of parental relationships satisfaction. Indeed, conducting interviews in Chapter 4 shows the value of these sorts of data collection methods, by obtaining an in-depth view of special educators' experiences about the TEN-DD intervention. Additionally, due to the need to shorten the survey to increase response rate, we did not use measures specific to parental relationships. Future researchers should consider the use of measures specific to parental relationships; especially in Chapter 2 it was evident that this area of research is still largely absent in the field of ASD research in the Arab context.

It was found in Chapter 4 that although the first researcher kept a reflective diary during data collection and discussed her own preconceptions to each interview with the second researcher of the study, positive reports from educators regarding training and mentoring visits should be viewed with caution. The first researcher was involved in training educators on the use of the TEN-DD intervention and provided mentoring visits over the intervention implementation period, and she also conducted the interviews with these educators. Future studies should seek to replicate conducting interviews with educators by an individual who is not involved in the research team. In addition, distribution of a questionnaire to educators alongside interviews might be beneficial and minimise this limitation.

While findings from Chapter 5 provided preliminary support for the TEN-DD numeracy intervention and the involvement of Arab parents trained in the implementation of numeracy skills at home, future research is needed to further substantiate the results of this study. We only focused on implementation of one stage of the TEN-DD intervention, thus the evaluation of the whole intervention, including a control group in the study design, is needed. Further, future research might examine the effectiveness of the TEN-DD intervention mediated by parents to their children with ASD over a longer period of implementation, as we implemented the intervention over a relatively short period. Additionally, the number of participants, only three parents and their children with ASD, makes it difficult to generalise findings from this study to other Arab parents of children with ASD. Future research would do well to evaluate the intervention with larger samples of parents and children. Furthermore, all three of the children were male and attending special schools. We recommended the replication of the study including parents of children with other genders, and children attending other educational settings.

From the findings of the intervention study it was noticed that more work is needed to find out how best to sustain support for parents. Additionally, we did not collect follow-up data, thus, it would be beneficial to administer a follow up test to children to assess whether the post-intervention gains are maintained. Moreover, it was not possible to provide overlaps to check that parents were delivering the intervention correctly, including recommended number and duration of sessions per week, although duration data sheets were used to try to ensure some fidelity of implementation. Therefore, collecting data on fidelity of implementation requires attention in future research.

We only explored parents' perceptions about the TEN-DD intervention. It is crucial to understand perceptions and views of all key stakeholders about interventions. Thus, exploring childrens' perceptions of the TEN-DD intervention is an additional area deserving further investigation in future research. Murphy and Cameron (2008) indicated that communication impairment is prevalent in individuals with intellectual and developmental disabilities. Thus, exploring the views of those unable to communicate in conventional ways would be challenging for researchers (Brewster, 2004). Indeed, children with disabilities who are unable to communicate are often excluded from interview-based research (Brewster, 2004; Stewart, Bradshaw, & Beadle-Brown, 2018). To involve individuals with intellectual and developmental disabilities and enhance research interviews by obtaining their views, researchers are now using many tools including Talking Mats (Cameron & Murphy, 2002; Stewart et al, 2018). This is a technique involving physically moving graphic symbols that are presented on a mat to assist individuals in expressing their views and facilitate discussion of a topic (Bell & Cameron, 2008; Brewster, 2004). It is based on three sets of picture symbols including: topics that are relevant to a subject, options relating to each topic, and emotions that aim to help express general feeling about each option including 'happy' represented by a smile, 'maybe' represented by a balancing hands, and 'sad' represented by a frown (Cameron & Murphy, 2002). Talking Mats was developed in the late 1990s by Joan Murphy to assist individuals with cerebral palsy and communication disorders to express their views and wishes (Murphy, 1997). The purpose of Talking Mats is not only to provide individuals with a means of communicating their views more easily, but also to help them to think about topics in various way (Brewster, 2004). It has been used for a variety of aims, for example accessing views of young people with learning disabilities about the choices available to them at times of transition (Cameron & Murphy, 2002), exploring socio-sexual knowledge in a person with severe learning disabilities and severe communication difficulties (Bell & Cameron, 2003), and investigating views of individuals with learning disabilities in research (Brewster, 2004). Cameron and Murphy (2002) found that Talking Mats is simple and enjoyable to use, and the participants can demonstrate their likes and dislikes and express their views on transition planning. Therefore, Talking Mats would be an effective tool that could help future researchers in gaining the views and perceptions of children with ASD on the TEN-DD intervention. Future research may also wish to examine the impact of using the TEN-DD intervention on children's other skills such as language and communication, as children's learning is extended beyond the planned intervention, with parents observing that children's speech, attitude to learning and concentration also improved during the implementation period.

In addition, a future stage of generating evidence for the effectiveness of the entire TEN-DD curriculum could be to conduct a randomised controlled trial (RCT) in the Jordanian context. RCTs are considered the "gold standard" for evidence-based interventions (Akobeng, 2005; Bhide, Shah, & Acharya, 2018; Kabisch, Ruckes, Seibert-Grafe, & Blettner, 2011), as they reduce the risk of selection bias, create a causal conclusion, and avoid possibly misleading findings from non-experimental work which is insufficiently controlled for selection bias (Hutchison & Styles, 2010; Sullivan, 2011). RCTs are a type of study design in which participants are randomly allocated to one of two groups: one (the experimental group) receives the intervention being tested, and the other (the comparison group or control) receives an alternative intervention or may receive no intervention. The two groups are then followed up to find whether there are any differences between them in outcome (Bhide et al, 2018; Kendall, 2003). Random allocation can be conducted either at the level of the individual or at a higher group or cluster level. In the individual randomised design participants are randomised as individuals to the intervention, while in the cluster randomised design, groups of people are assigned to receive an intervention or not (Hahn, Puffer, Torgerson, & Watson, 2005; Torgerson & Torgerson, 2001). In educational research, the cluster level is the common method of allocation. The cluster randomised design helps to avoid the problem of contamination. Participants allocated to a control group may unintentionally receive some features of the intervention if they are close to the experimental group. A cluster might be at the level of a class but more possibly at the level of a school (Hahn et al, 2005; Hutchison & Styles, 2010; Torgerson & Torgerson, 2001). Tzanakaki and colleagues (2014b) indicated that it is feasible to conduct a RCT study of the TEN-DD intervention within applied educational settings for individual children with intellectual disabilities or autism.

Ultimately, I would like to implement the whole TEN-DD curriculum with children with ASD in Jordan using a RCT design, in particular the cluster randomised design at the level of school classes. To ensure that such a RCT would be feasible in the Jordanian context I will first conduct a pilot study to investigate the feasibility of the entire TEN-DD curriculum, after translating the other stages, for use with children with ASD in school settings. According to Kendall (2003), pilot studies can direct decisions about designing approaches to recruitment and outcome measurement. They also provide information on what the recruitment will look like, including number of accessible participants and their willingness to take part. In addition, pilot studies assist researchers in exploring any methodological problems connected with using the intervention or measuring outcome variables (Kendall, 2003). Pilot studies are a version of the main study that is conducted in miniature to examine if the components of the main study would work collectively. They are focused on the procedures of the main study to ensure that recruitment, randomisation, treatment, and follow-up tests all run without problems or difficulties (Arain, Campbell, Cooper, & Lancaster, 2010).

Personal Reflections

When I obtained my master's degree in special education, I had the opportunity to work with children with autism in a special centre in Jordan for eight months. I observed that autistic children were left behind. Indeed, there were limited services and educational programmes. Furthermore, parents of children with autism encountered extensive challenges when trying to cope with their children's condition, and to identify and access appropriate services. Parents suffered from discrimination and social stigma. There was a lack of awareness about autism. During the eight months of working with children with autism, I became very interested in the field of autism. I kept asking myself how those children and their families could be supported more effectively?

After that I had the opportunity to work for six years as a lecturer in special education at one of the Jordanian universities. During my work as a lecturer I found that special education programmes were of poor quality. The programme did not include, for example, any type of evidence-based interventions, in particular educational interventions. Experiences of families of children with special needs including autism have been neglected from the programme. During my time of working in the university, I was awarded a scholarship in the field of autism. I thought that it is the time to have some action. I am extremely fortunate to have had the opportunity to explore the field of autism within the research reported here. I have had the opportunity to explore different research methods, and in doing so I have had to go through a whole new learning experience. Doing this thesis has provided me with new skills and knowledge, especially regarding mathematics intervention. Indeed, being part of a wider research project that aimed to evaluate a numeracy intervention with pupils with ASD, where quantitative outcomes were part of another PhD student's thesis and I focused on the qualitative outcomes, provided me with the opportunity to learn about the numeracy intervention, get involved in testing children's numeracy skills, and train education staff in a special school. All the training that I obtained assisted me in conducting an initial numeracy study in the context of Arab families in the UK (Chapter 5), which will in turn prepare me for carrying out numeracy research with children with ASD in the Jordanian context.

If I had known then what I know now, I might have supported autistic children's education more effectively when I worked with them. Indeed, doing this thesis means that I will be able to better support children with autism and their families in Jordan by putting into practice some of the thesis findings. I could also contribute to special education training programmes in the University context and direct more attention to families of children with autism in Jordan.

Contribution that others made to each study

Chapter 2

Dr. Gemma Gray contributed to the following:

- The process of search strategy including screening, eligibility, and included. For example, excluded studies that did not meet inclusion criteria based on title and abstract screening and applied inclusion criteria to studies after obtaining full text copies.
- Data extraction and appraisal of study quality. She checked data extraction on a sample of included studies (20%). She also quality assessed a sample of 20% of included studies from the searches originally conducted in April 2016.

Chapter 3

Dr Tom Bailey contributed to the study by providing a supervisory support during the analysis stage (e.g., manipulating the data and regression analyses) of the study.

Chapter 4

Dr Louise Denne contributed to the study by providing supervision support during the analysis stage of the interviews data.

Mrs Magdalena Apanasionok contributed to the following:

- Delivered the training sessions on the TEN-DD to the special educators who delivered the intervention.
- Provided mentoring visits to observe the TEN-DD sessions and offer support, troubleshoot if needed and provide feedback.
- Listened to the recordings and went through all the transcripts.
- Checked master themes and the thematic map. She asked to create a mind map that includes key ideas that came out from her reading through all the transcripts and then check that if her overall impressions come out in the themes that the first researcher had identified.

Dr Corinna Grindle contributed to the study by delivering the training sessions on the TEN-DD to the special educators who delivered the intervention.

The interpretations of themes were collaboratively discussed with the research team throughout the period of analysis and during write-up of the research study. Further, Dr Corinna and Dr Louise had read through the paper and provided their feedback.

Chapter 5

Dr Corinna Grindle contributed to the following:

- Prepared slides/content of the training session on the TEN-DD with the first researcher.
- Delivered the training session on the TEN-DD to the mothers who delivered the intervention to their children.

- Provided feedback on modification that made to generalisation section in the teaching plans in order to be more appropriate for the home context.
- Read through the paper and provided her feedback.

Conclusions

This thesis contributes new knowledge to the field of ASD in the context of Arab countries and cultures, in particular children with ASD and their families who live in the UK. It has provided a greater understanding of previous research conducted on social, educational, and psychological domains related to individuals with ASD and their family members in order to identify gaps in the research evidence base. Accordingly, it is well recognised that there is a scarcity of research conducted on interventions, particularly educational interventions. There are few data on services provided to individuals with ASD and their families in terms of organisations, effectiveness, or consumer perspectives. Further, there is limited research conducted on individuals with ASD and their family members who live in non-Arab countries. Therefore, this thesis has attempted to explore these areas by conducting research on support needs of Arab families of children with ASD, and an evaluation of a numeracy intervention with Arab children with ASD, by training and supporting their parents to deliver the intervention at home. Additionally, exploring experiences and views of one of the key stakeholders, special educators, on using the numeracy intervention with their pupils with ASD in the classroom. This thesis asks researchers, practitioners, and policy makers to consider that children with ASD and their families in the context of Arab countries and cultures do matter. This thesis also represents a starting point for future research in the field of ASD in the Arab context.

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Appendices

Appendix A: Protocol of the systematic scoping review

Review Questions:

1- What social, educational and psychological research has been conducted on individuals with ASD in Arab countries and cultures?

Objective (1): To review and analyse social, educational and psychological research have been conducted on individuals with ASD in Arab countries and cultures.

Objective (2): To categorize which areas on social, educational and psychological research about individuals with ASD have been researched.

2- What social, educational and psychological research has been conducted on family members of individuals with ASD in Arab countries and cultures?

Objective (1): To review social, educational and psychological research have been conducted on family members of individuals with ASD in Arab countries and cultures.

Objective (2): To categorize which field of social, educational and psychological research have been conducted on family members of individuals with ASD in Arab countries and cultures.

Searches:

The following electronic database will use in searching the relevant literature: PsycINFO, MEDLINE, ERIC, Social Science Citation Index, EBESCO, EMBASE, Web of Science and Google Scholar.

The following search terms will be used:

1- Autis*
2- ASD
3- Asperger*
4- pervasive developmental disorder*
5- PDD
6- Arab (Arab*)
7- Algeria*
8- Egypt*
9- Libya*
10- Tunisia*
11- Morocco*
12- Mauritania*

13- Sudan*
14- Somal*
15- Djibouti*
16- Bahrain*
17- Emirates
18- UAE
19- Oman*
20- Kuwait*
21- Qatar*
22- Saudi*
23- KSA
24- Yemen*
25- Jordan*
26- Syria*
27- Iraq*
28- Gaza
29- Leban*
30- "West bank"
31- Gulf
32- "Middle East"

Search 1: each term (1-5) to be included in a search separated with OR (i.e., Autis* OR ASD OR etc).
Search 2: each term (6-32) to be included in a search separated each term with OR.
Search 3: combine searches 1 and 2 with AND.

Limits and restrictions: No limits and restrictions will be applied regarding publication date or study design.
Reference searching: reference searches will be conducted by checking the reference lists and citation recorders of included studies and systematic reviews to find any potentially eligible studies that the databases may have missed.

Inclusion criteria:

1- All study designs, including case series, and case studies.

2- Study had to focus on; social, educational, and psychological issues related to individuals with ASD and their family members in an Arab country or culture.
3- Participants in studies had to be Arab individuals with ASD or their family members.
4- Studies published in English or Arabic language.

Types of participants / population:

1- Individuals with autism, ASD, Asperger syndrome, PDD/PDD-NOS, and/or their family members in Arab countries and cultures.
2- No restrictions on age and gender.

Exclusion criteria:

➢ Medical studies of individuals and adults with ASD and/ or their family members in Arab countries and cultures which include:

- Medical causes such as:

  1- Genetic factors.
  2- Metabolic disorders (untreated phenylketonuria [PKU]).
  3- Toxic and environmental factors.
  4- Neurologic disorders (abnormalities in brain structure or function).

- Medical diagnosis which includes:

  1- Biological markers such as Immune blood markers, Immune urine markers, heavy metal markers urine, oxidative stress blood markers, oxidative stress urine markers, heavy metal markers blood and heavy metal markers urine.
  2- Physical assessments, for instance hearing tests and Physical exam, including head circumference, weight and height measurements.
  3- Laboratory tests such as genetic test, blood and urine test.

- Medical treatment, for example:

  1- Dietary treatment.
  2- Drugs.
  3- Acupuncture therapy.
  4- Chelation therapy which helps to remove metals and toxins from the body and formulates nutritional supplements.

- Physical health condition problems such as:

  1- Food and skin allergies.

2- Vitamins deficiency. (D and B12).
3- Gluten sensitivity.
4- G6PD deficiency.
5-Low serum level in the blood.
6- Low growth hormone levels.

- Systematic reviews.
- Papers which are research thesis, books, book chapters, conferences papers, and meeting abstract.
- Insufficient methodological or data analysis information is provided in the paper.

Appendix B: Survey- Support needs of Arab families of children with ASD living in the UK

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Support needs study of Arab families of children with autism spectrum disorder living in the United Kingdom

Primary caregivers survey

Part I: Demographic Questions

Questions about your child with autism spectrum disorder

We would like to ask you some questions about your child with autism spectrum disorder:

1. How many children under 18 years of age are there in your family and how many children under 18 years of age have autism spectrum disorder?

	Number
Children (under 18 years of age)	…………
Children with autism spectrum disorder (under 18 years of age)	…………

Note: *If there is more than one child with autism spectrum disorder in your family who are aged between 4 years and 15 years 11 months, please choose the* ***oldest*** *one to focus on for this survey.*

2. What is the gender of your child with autism spectrum disorder? (Please select ONE)

Male ☐

Female ☐

Other (Please describe if you wish) ☐ ………………………………………………………………….

Prefer not to answer ☐

3. How old is your child with autism spectrum disorder?

Years ………..

Months ………..

4. If you have been given an autism-related diagnosis for your child which of the following best describes that diagnosis? (Please select ONE)

Autism ☐

Asperger Syndrome ☐

Pervasive Development Disorder - Not otherwise specified (PDD-NOS) ☐

Childhood Disintegrative Disorder ☐

Other (please specify): ………………………………………………………………………………………….

5. If you have been given a diagnosis for your child how long did it take from raising your initial concerns to obtaining that diagnosis? (Please select ONE)

About 3 months ☐	About 6 months ☐
About a year ☐	More than a year ☐

6. Do you feel it has got easier or harder to access services for your child with autism spectrum disorder in the last year? (Please select ONE)

Much easier ☐

Somewhat easier ☐

No difference ☐

Somewhat harder ☐

Much harder ☐

Questions about you

7. Please indicate your relationship to the child with autism spectrum disorder: (Please select ONE)

Biological mother	☐	Biological father	☐
Adoptive mother	☐	Adoptive father	☐
Stepmother	☐	Stepfather	☐
Foster mother	☐	Foster father	☐
Grandmother	☐	Grandfather	☐

Other (please specify): …………………………………………………………………………………………

8. To which age group do you belong? (Please select ONE)

Under 24 years	☐	25-34	☐	35-44	☐
45-54	☐	55-64	☐	65 or over	☐

9. How do you identify your gender? (Please select ONE)

Male ☐

Female ☐

Other (Please describe if you wish) ☐ …………………………………………………………………………

Prefer not to answer ☐

10. From which country would you say that you draw your Arab identity? (Please select ONE)

Egypt	☐	Algeria	☐
Sudan	☐	Iraq	☐
Morocco	☐	Saudi Arabia	☐
Yemen	☐	Syria	☐
Tunisia	☐	Somalia	☐

United Arab Emirates ☐
Libya ☐
Lebanon ☐
Kuwait ☐
Qatar ☐
Djibouti ☐
Jordan ☐
Palestine ☐
Oman ☐
Mauritania ☐
Bahrain ☐
Comoros ☐

Other (please specify): ……………………………………………………………………………………

11. Please tell us in which country you were born: (Please select ONE)

The United Kingdom ☐

Another country (please specify) ☐ ………………………………………………………………………

12. If you were born in a country other than the UK, please tell us how long you have lived in the UK:

…………………… years

13. Please select the highest level of your educational qualifications: (Please select ONE)

No qualifications ☐

School leaving qualifications (e.g., in the UK, GCSEs or A levels) ☐

Vocational studies/ college degree or university degree ☐

Masters/Doctoral degree ☐

Don’t know ☐

14. Please select one option which describes your employment status (Please select ONE)

In a job and currently working for an employer ☐

On maternity/ paternity/ parental leave from a job ☐

Self-employed ☐

A full-time student ☐

Doing voluntary work ☐

Looking after home and family ☐

Unemployed ☐

Doing something else (please specify) ……………………………………………………..

15. What is your current marital status? (Please select ONE)

Married and living with spouse/civil partner ☐

Living with partner ☐

Divorced/Separated/Single/Widowed/Not currently living with partner ☐

We would like to ask you some questions about your relationship with a spouse/partner

16. How often do you and your [husband/wife/partner] disagree over issues relating to your child with autism spectrum disorder? (Please select ONE)

Never ☐

Less than once a week ☐

Once a week ☐

Several times a week ☐

Once a day ☐

More than once a day ☐

Can’t say ☐

17. Here is a scale from 1-7 where ‘1’ means that you are very unhappy and ‘7’ means that you are very happy. Please circle the number which best describes how happy or unhappy you are with your relationship with your spouse/partner, all things considered?

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Very unhappy						very happy	Can’t say

18. How is your health in general? (Please select ONE)

Very good ☐

Good ☐

Fair ☐

Bad ☐

Very bad ☐

Questions about your household

19. In total how many adults above 18 years of age currently live in your home, including yourself?

Recent data from research with families of children with special needs have shown that a family’s financial resources are important in understanding family members’ views and experiences. With this in mind, we would be very grateful if you could answer the additional question below. We are not interested in exactly what your family income is, but we would like to be able to look at whether those with high versus lower levels of financial resources have different experiences.

20. What is your total weekly household income (after any deductions e.g. income tax), including income from paid work, pension, Social Services Benefits (e.g. Job Seekers Allowance, Carers’ Allowance, Attendance Allowance, Tax Credits, Housing Benefits, Pension Credits) etc.? (Please select ONE)

£200 or less	☐	Between £201 and £300	☐
Between £301 and £400	☐	Between £401 and £500	☐
Between £501 and £600	☐	Between £601 and £700	☐

Between £701 and £800	☐	Between £801 and £900	☐
Between £901 and £1,000	☐	Over £1000	☐

21. How well would you say you {and your husband/wife/partner} are managing financially these days?

Would you say you are…? (Please select ONE)

Living comfortably	☐	Doing alright	☐
Just about getting by	☐	Finding it quite difficult	☐
Finding it very difficult	☐		

22. Suppose you only had one week to raise £2000 for an emergency, which of the following best describes how hard it would be for you to get that money? (Please select ONE)

I could easily raise the money	☐
I could raise the money, but it would involve some sacrifices (e.g. reduced spending, selling a possession)	☐
I would have to do something drastic to raise the money (e.g. selling an important possession)	☐
I don't think I could raise the money	☐

Part 2: Your child's Adaptive behaviour

This section asks you questions about your child's adaptive behaviour in terms of support needs, communication, socialization, and self-help skills. Please read each statement listed below and select which skill level your child has.

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

Requires support for almost all aspects of life	☐
Requires support for most, but not all, aspects of life	☐

Requires support for some aspects of life ☐

Requires support for only a few aspects of life ☐

Does not require support ☐

2. How much does your child understand spoken language?

Able to understand very little spoken language ☐

Able to understand some basic language and simple instructions in familiar contexts (e.g. sit down) ☐

Able to understand most basic instructions and questions ☐

Able to understand most routine everyday language ☐

Able to understand complex language about a wide range of topics ☐

3. How much does your child use spoken language to communicate?

Able to use very little meaningful speech ☐

Able to communicate basic needs and wants ☐

Able to communicate needs, wants and some ideas ☐

Able to communicate about a limited range of topics in a meaningful way ☐

Able to communicate about a wide variety of topics in a meaningful way ☐

4. How much does your child use alternative methods of communication to communicate? (e.g., signing, symbol systems, PECS) (If applicable)

Able to communicate very little using alternative means of communication ☐

Able to communicate basic needs and wants ☐

Able to communicate needs, wants and some ideas ☐

Able to communicate about a limited range of topics in a meaningful way ☐

Able to communicate about a wide variety of topics in a meaningful way ☐

5. How much does your child engage in social interactions with familiar adults?

Shows little or no interest in social interactions with familiar adults ☐

Shows limited social interest but will sometimes respond to familiar adults ☐

Shows some interest, responds to others, but does not initiate social interactions with familiar adults ☐

Shows clear social interest, responds to others, and sometimes initiates social interactions with familiar adults ☐

Engages in a wide range of social interactions involving both responding and initiating social contact with familiar adults ☐

6. How much does your child engage in social interactions with other children?

Shows little or no interest in social interactions with other children ☐

Shows limited social interest but will sometimes respond to other children ☐

Shows some interest, responds to others, but does not initiate social interactions with other children ☐

Shows clear social interest, responds to others, and sometimes initiates social interactions with other children ☐

Engages in a wide range of social interactions involving both responding and initiating social contact with other children ☐

7. Please select the most accurate description of your child's skills in eating:

Needs complete assistance with eating ☐

Eats with fingers ☐

Can use spoon but may be messy ☐

Uses spoon and fork ☐

Eats completely independently with proper use of all cutlery ☐

8. Please select the most accurate description of your child's skills in toileting:

Wears diapers day and night ☐

Wears diaper but indicates when needs changing ☐

Indicates or asks to use toilet, but does not go independently ☐

Toilet trained in daytime (occasional accidents); wears diaper or pull-up at night ☐

Completely toilet trained day and night ☐

9. Please select the most accurate description of your child's skills in dressing:

Needs complete assistance dressing and undressing ☐

Cooperates with dressing (e.g. raising arms) ☐

Can remove or pull on/up clothes ☐

Can dress self quite well but needs help with buttons, zippers, etc. ☐

Can dress and undress self completely ☐

*Adrienne Perry, 2014

Part 3: Your Family needs

This section asks you questions about your family's needs in terms of information and support in relation to your child with autism spectrum disorder. Please read each statement listed below and select (✓) how much support you as a family need in each of the areas.

Topics	***No support needed***	***A little support needed***	***A lot of support needed***
Information 1. How children with autism spectrum disorder grow and develop			

Topics	***No support needed***	***A little support needed***	***A lot of support needed***
2. How to play or talk with my child with autism spectrum disorder			
3. How to teach my child with autism spectrum disorder			
4. How to handle my child’s behaviour			
5. Information about any condition or disability my child with autism spectrum disorder might have			
6. Information about services that are presently available for my child with autism spectrum disorder			
7. Information about the services my child with autism spectrum disorder might receive in the future			
Family and social support 1. Talking with someone in my family about concerns			
2. Having friends to talk to			
3. Finding more time for myself			
4. Helping my spouse accept any condition our child with autism spectrum disorder might have			
5. Helping our family discuss problems and reach solutions			
6. Helping our family support each other during difficult times			
7. Deciding who will do household chores, child care, and other family tasks			

Topics	***No support needed***	***A little support needed***	***A lot of support needed***
8. Deciding on and doing family recreational activities			
Financial assistance 1. Paying for expenses such as food, housing, medical care, clothing, or transportation.			
2. Getting any special equipment my child needs			
3. Paying for therapy, day care, or other services my child needs			
4. Counselling or help in getting a job			
5. Paying for babysitting or respite care			
6. Paying for toys that my child needs			
Explaining to Others 1. Explaining my child's condition to my parents or my spouse's parents			
2. Explaining my child's condition to his or her siblings			
3. Knowing how to respond when friends, neighbours, or strangers ask questions about my child with autism spectrum disorder			
4. Explaining my child's condition to other children			
5. Finding reading material about other families who have a child like mine			
Child Care			

Topics	***No support needed***	***A little support needed***	***A lot of support needed***
1.Locating babysitters or respite care providers who are willing and able to care for my child with autism spectrum disorder			
2. Locating a day care program or preschool for my child with autism spectrum disorder			
3. Getting appropriate care for my child with autism spectrum disorder in a mosque, church or synagogue during religious services			
Professional Support 1. Meeting with an imam, priest, or rabbi			
2. Meeting with a counsellor (psychologist, social worker, psychiatrist)			
3. More time to talk to my child's teacher or therapist			
Community Services 1. Meeting & talking with other parents who have a child with autism spectrum disorder like mine			
2. Locating a doctor who understands me and my child's needs			
3. Locating a dentist who will see my child			

Bailey et al., 1992.

<u>Part 4: Strengths and Difficulties Questionnaire</u>

This section asks you about the strengths and difficulties of your child with autism spectrum disorder.

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over **<u>the last six months</u>**.

	Not true	**Somewhat true**	**Certainly true**
Considerate of other people's feelings			
Restless, overactive, cannot stay still for long			
Often complains of headaches, stomach-aches or sickness			
Shares readily with other children (treats, toys, pencils etc)			
Often has temper tantrums or hot tempers			
Rather solitary, tends to play alone			
Generally obedient, usually does what adults request			
Many worries, often seems worried			
Helpful if someone is hurt, upset or feeling ill			
Constantly fidgeting or squirming			
Has at least one good friend			
Often fights with other children or bullies them			
Often unhappy, down-hearted or tearful			
Generally liked by other children			
Easily distracted, concentration wanders			
Nervous or clingy in new situations, easily loses confidence			
Kind to younger children			
Often lies or cheats			
Picked on or bullied by other children			
Often volunteers to help others (parents, teachers, other children)			
Thinks things out before acting			

	Not true	**Somewhat true**	**Certainly true**
Steals from home, school or elsewhere			
Gets on better with adults than with other children			
Many fears, easily scared			
Sees tasks through to the end. good attention span			

*Robert Goodman, 2005

Part 5: Your Well-Being

Read each item and please tick the box (✓) which comes closest to how you have been feeling, on average, **in the past week**. Don't take too long over your answers; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or wound up

Most of the time	A lot of the time	From time to time	Not at all
☐	☐	☐	☐

2. I get a sort of frightened feeling as if something bad is about to happen

Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
☐	☐	☐	☐

3. Worrying thoughts go through my mind

A great deal of the time	A lot of the time	From time to time but not often	Only occasionally
☐	☐	☐	☐

4. I can sit at ease and feel relaxed

Definitely	Usually	Not often	Not at all
☐	☐	☐	☐

5. I get a sort of frightened feeling like butterflies in the stomach

Not at all	Occasionally	Quite often	Very often
☐	☐	☐	☐

6. I feel restless and have to be on the move

Very much indeed	Quite a lot	Not very much	Not at all
☐	☐	☐	☐

7. I get sudden feelings of panic

Very often indeed	Quite often	Not very often	Not at all
☐	☐	☐	☐

8. I still enjoy the things I used to enjoy

Definitely as much	Not quite as much	Only a little	Hardly at all
☐	☐	☐	☐

9. I can laugh and see the funny side of things

As much as I always could	Not quite so much now	Definitely not so much now	Not at all
☐	☐	☐	☐

10. I feel cheerful

Not at all	Not often	Sometimes	Most of the time
☐	☐	☐	☐

11. I feel as if I am slowed down

Nearly all the time	Very often	Sometimes	Not at all
☐	☐	☐	☐

12. I have lost interest in my appearance

Definitely	I don’t take as much care as I should	I may not take quite as much care	I take just as much care
☐	☐	☐	☐

13. I look forward with enjoyment to things

As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
☐	☐	☐	☐

14. I can enjoy a good book or radio or TV programme

Often	Sometimes	Not often	Very seldom
☐	☐	☐	☐

*Zigmond and Snaith, 1983

End of Survey

Thank you for completing the survey

Please return the survey with your consent form using the pre-post envelope in your pack

Appendix C: Survey (Arabic version)- Support needs of Arab families of children with ASD living in the UK

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استبانة دعم احتياجات الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد الذين يعيشون في المملكة المتحدة

استبانة لمقدمي الرعاية الأولية

الجزء الأول: الأسئلة الديمغرافية (العامة)

أسئلة حول طفلك المُشخص باضطراب طيف التوحد

نَودُّ منك التَفضُل بالإجابة عن بعض الأسئلة العامّة المُتعلقة بطفلك المُشخص باضطراب طيف التوحد وذلك بوضع إشارة ✓ أمام الخيار المناسب أو بملء الفراغات الموجزة:

1. كم عدد الأطفال في عائلتك الذين تقل أعمارهم عن 18 سنة وكم عدد المُشخصين باضطراب طيف التوحد ؟

الأطفال (أقل من 18 سنة) ....
الأطفال المُشخصين باضطراب طيف التوحد (أقل من 18 سنة) ....

(***ملاحظة**: في حال وجود أكثر من طفل لك مُشَخص باضطراب طيف التوحد (يتراوح أعمارهم بين4 سنوات إلى 15 سنة و 11 شهراً) ، يُرجى منك الإجابة فقط عن الطفل الأكبر).

2. ماهو جنس طفلك المُشخص باضطراب طيف التوحد ؟ من فضلك اختر إجابة واحدة

ذكر ☐
أنثى ☐
أخرى (يرجى الوصف إذا كنت ترغب) ☐...
أفضل عدم الإجابة ☐

3. كم عمر طفلك المُشخص باضطراب طيف التوحد ؟

العمر .... بالسنوات

العمر

بالأشهر ....

4. إذا تم إعطاء طفلك تشخيصاً مرتبطاً بإحدى حالات التوحد: أي من التالية يعتبر أكثر وصفاً لذلك التشخيص؟ من فضلك اختر إجابة واحدة

توحد ☐

اضطراب النمو الشامل غير المحدد ☐

متلازمة أسبيرجر ☐

اضطراب الطفوله التحللي/التفككي ☐

أخرى (يرجى التحديد):- ....

5. إذا تم تشخيص طفلك، فكم كانت المدة الزمنية ما بين ظهور مخاوفك الأولية حول حالة طفلك وحصولك على التشخيص؟ من فضلك اختر إجابة واحدة

تقريباً ثلاثة أشهر ☐

واحدة سنة تقريباً ☐

تقريباً ستة أشهر ☐

أكثر من سنة واحدة ☐

6. هل تشعر أنه قد أصبح من الأسهل أو الأصعب عليك الحصول على خدمات لطفلك المُشخص باضطراب طيف التوحد خلال العام الماضي؟ من فضلك اختر إجابة واحدة

أسهل بكثير ☐

إلى حد ما أسهل ☐

لا فرق يذكر ☐

إلى حد ما أصعب ☐

أصعب بكثير ☐

أسئلة حولك أنت

7. من فضلك حدد صلتك بالطفل المُشخص باضطراب طيف التوحد ؟ من فضلك اختر إجابة واحدة

أم بيولوجية (الوالدة) ☐

أم بالتبني ☐

زوجة الأب ☐

أب بيولوجي (الوالد) ☐

أب بالتبني ☐

زوج الأم ☐

أم حاضنة (مربية) ☐

جدة ☐

أب حاضن (مربي) ☐

جد ☐

8. إلى أي فئة عمرية تنتمي؟ من فضلك اختر إجابة واحدة

أقل من 24 سنة ☐

25-34 ☐

35-44 ☐

45-54 ☐

55-64 ☐

65 سنة فما فوق ☐

9. ما هو جنسك؟ من فضلك اختر إجابة واحدة

ذكر ☐

أنثى ☐

أخرى (يرجى الوصف إذا كنت ترغب) ☐..

أفضل عدم الإجابة ☐

10. إلى أي دولة تعود هويتك العربية؟ من فضلك اختر إجابة واحدة

مصر ☐

السودان ☐

المغرب ☐

اليمن ☐

تونس ☐

الإمارات العربية المتحدة ☐

الجزائر ☐

العراق ☐

المملكة العربية السعودية ☐

سوريا ☐

الصومال ☐

الأردن ☐

ليبيا ☐

لبنان ☐

الكويت ☐

قطر ☐

جيبوتي ☐

فلسطين ☐

سلطنة عُمان ☐

موريتانيا ☐

البحرين ☐

جزر القمر ☐

أخرى (يرجى التحديد):- ....

11. من فضلك هل ممكن أن تخبرنا في أي دولة ولدت؟ من فضلك اختر إجابة واحدة

المملكة المتحدة ☐

دولة أخرى (يرجى التحديد) ☐

(يرجى التحديد):- ....

12. إذا ولدت في دولة غير المملكة المتحدة، هل لك أن تخبرنا عدد سنوات الاقامة في المملكة المتحدة:

______ سنوات

13. من فضلك اختر أعلى مستوى لمؤهلاتك العلمية:- من فضلك اختر إجابة واحدة

لا يوجد مؤهلات ☐

التعليم المدرسي(التعليم الأساسي, التعليم الثانوي او التعليم المهني) ☐

شهادة إجتياز إختبار الثانوية العامة ☐

دراسات مهنية/ درجة الشهادة الجامعية المتوسطة (كليات المجتمع) أو الدرجة الجامعية الأولى (درجة البكالوريوس) ☐

درجة الماجستير/ الدكتوراة ☐

لا أعرف ☐

14. من فضلك اختر الخيار الأمثل لحالتك الوظيفية؟ من فضلك اختر اجابة واحدة

في وظيفة و حالياً أعمل لصالح رب العمل ☐

في اجازة أمومة/ أبوة/ الإجازة الوالدية من العمل ☐

أعمل لحسابي الخاص ☐

طالب بدوام كامل ☐

أقوم بعمل تطوعي ☐

أقوم برعاية البيت و الأسرة ☐

عاطل عن العمل ☐

أقوم بعمل آخر (يرجى التحديد) ☐

(يرجى التحديد):- ....

15. ما هي حالتك الإجتماعية الحالية؟ من فضلك إختر إجابة واحدة

متزوج وأعيش مع زوج/ شريك مدني ☐

أعيش مع شريك ☐

مطلق/منفصل/أعزب/ أرمل/ لا أعيش حالياً مع شريك ☐

نَودُّ منك التَفضُل بالإجابة عن بعض الأسئلة المُتعلقة بعلاقتك مع زوجك/زوجتك أو شريكك/ شريكتك.

16. كم في الغالب تختلف أنت و(زوجك/زوجتك/شريكك/شريكتك) على قضايا تخص طفلكم المُشخص باضطراب طيف التوحد ؟ من فضلك اختر إجابة واحدة

لم يحصل أبداً ☐

أقل من مرة في الأسبوع ☐

مرة في الأسبوع ☐

عدة مرات في الأسبوع ☐

مرة باليوم ☐

أكثر من مرة باليوم ☐

لا أستطيع الإفصاح ☐

17. يوجد هنا مقياس من 1-7 حيث "1" يعني أنك غير سعيد مطلقاً و "7" تعني أنك سعيد جداً. يرجى وضع دائرة حول الرقم الذي يصف إلى أي حد أنت سعيد أو غير سعيد في علاقتك مع زوجك/ شريكك مع الاخذ بعين الاعتبار كل الأمور؟

1	2	3	4	5	6	7	8
غير سعيد مطلقاً						سعيد جداً	لا أستطيع الإفصاح

18. ما حالتك الصحية بشكل عام؟ من فضلك اختر اجابة واحدة

جيدة جداً ☐

جيدة ☐

متوسطة ☐

سيئة ☐

سيئة جداً ☐

أسئله حول منزلك

19. كم عدد الأفراد الذين تزيد اعمارهم عن 18 سنة المقيمين حالياً في منزلك، بما فيهم أنت؟

الأفراد (فوق 18سنة)..................................

تشير نتائج دراسات حديثة حول أسر الأطفال ذوي الإحتياجات الخاصة أن موارد الأسرة المالية لها أهمية في فهم وجهات نظر أفراد الأسرة و خبراتهم. وبناءً على ذلك سنكون ممتنين لك إذا أمكن الإجابة عن الأسئلة التالية. نحن لسنا مهتمين بمعرفة دخلك على وجه الدقة، لكن نود أن نعرف إذا كان أصحاب الدخل العالي و المنخفض لديهم خبرات مختلفة.

20. من فضلك ما هو مجموع دخل أسرتك **الأسبوعي** (بعد كل الإقتطاعات، مثل ضريبة الدخل)، شاملاً الدخل من العمل، ومعاش التقاعد و عوائد الضمان الإجتماعي (مثل بدل إعانة الباحثين عن عمل و بدل إعانة مقدمي الرعاية، و بدل الإعفاءات الضريبية، إعانات السكن، ائتمان التقاعد) وما شابه ذلك؟ من فضلك اختر إجابة واحدة

£200 أو أقل ☐ £201–£300 ☐

£301–£400 ☐ £401–£500 ☐

£501–£600 ☐ £601–£700 ☐

£701–£800 ☐ £801–£900 ☐

£901–£1,000 ☐ فوق£1000 ☐

21. كيف ترى قدرتكما (أنت و زوجك/ زوجتك/ شريكك/ شريكتك) على إدارة أموركم المالية هذه الأيام؟
هل يمكن القول أنكما ..... من فضلك اختر إجابة واحدة

تعيشان بشكل مريح ☐

أنكم بحالة حسنة ☐

فقط تحصِّلان الحاجات الأساسية ☐

تجدانها صعبة إلى حد ما ☐

تجدانها صعبة جداً ☐

22. لنفترض أن لديك أسبوعاً واحداً فقط لجمع مبلغ £2000 لظرف طارئ، أي من الخيارات التالية يصف إلى أي حد يصعب عليك الحصول على ذلك المبلغ؟ من فضلك اختر إجابة واحدة

بسهولة يمكنني جمع المبلغ ☐

يمكنني جمع المبلغ ولكن هذا سيتطلب بعض التضحيات (مثل تقليل المصروف أو بيع ممتلكات) ☐

سيتطلب الأمر القيام بأمر حاسم لجمع المبلغ (مثل بيع ممتلكات مهمة) ☐

لا أعتقد أنني أستطيع جمع المبلغ ☐

الجزء الثاني: السلوك التكيفي لطفلك

في هذا الجزء سنطرح عليك أسئلة حول سلوك طفلك التكيفي من حيث دعم الإحتياجات، التواصل، الإندماج في المجتمع، و المهارات الشخصية. من فضلك إقرأ جيداً الفقرات كما مدرج أدناه واختر المستوى المناسب لمهارة طفلك.

1. ماهو مستوى المساعدة أو الدعم الذي يحتاجه طفلك أثناء ممارسته مهارات الحياة اليومية، على سبيل المثال (إستخدام الحمام، إرتداء الملابس، تناول الطعام):-

أ. يحتاج إلى دعم أثناء ممارسته كل مهارات الحياة اليومية. ☐

ب. يحتاج إلى دعم أثناء ممارسته معظم مهارات الحياة اليومية و ليس جميعها. ☐

ج. يحتاج إلى دعم أثناء ممارسته بعض مهارات الحياة اليومية. ☐

د. يحتاج إلى دعم أثناء ممارسته قليل من مهارات الحياة اليومية. ☐

هـ. لا يحتاج إلى دعم. ☐

2. كم قدره طفلك على فهم اللغه المنطوقه:-

أ. قادر على فهم القليل جداً من اللغة المنطوقة. ☐

ب. قادر على فهم بعض من أساسيات اللغة و التعليمات البسيطة في سياقات مألوفة على سبيل المثال(اجلس). ☐

ج. قادر على فهم معظم التعليمات الأساسية والاسئلة. ☐

د. قادر على فهم اللغة المستخدمة في الحياة اليومية. ☐

هـ. قادر على فهم لغة معقدة حول مواضيع متعددة. ☐

3. كم قدره طفلك على استخدام اللغة المنطوقة للتواصل:-

أ. قادر على استخدام كلام قليل جداً ذو معنى. ☐

ب. قادر على التعبير عن حاجاته ورغباته الأساسية. ☐

ج. قادر على التعبير عن حاجاته ورغباته الأساسية وبعض الأفكار. ☐

د. قادر على التعبير عن مواضيع محددة بطريقة مفهومة. ☐

هـ. قادر على التعبير عن مواضيع متعددة بطريقة مفهومة. ☐

4. إلى أي حد يستخدم طفلك وسائل تواصل بديلة على سبيل المثال (استخدام الاشارة، الرموز،PECS) .
(يرجى الاجابة اذا طفلك يستخدم وسائل تواصل بديلة)

أ. قادر على التواصل القليل جدا باستخدام وسائل بديلة. ☐

ب. قادر على التواصل والتعبير عن حاجاته ورغباته الاساسية . ☐

ج. قادر على التواصل والتعبير عن حاجاته ورغباته الأساسية وبعض الأفكار. ☐

د. قادر على التواصل والتعبير عن مواضيع محددة بطريقة مفهومة. ☐

هـ. قادر على التواصل والتعبير عن مواضيع متعددة بطريقة مفهومة. ☐

5. ماهو مستوى إندماج طفلك في التفاعلات الإجتماعية مع الكبار المألوفين لديه؟

أ. يظهر القليل أو عدم الإهتمام في التفاعلات الإجتماعية مع الكبار المألوفين. ☐

ب. يظهر إهتماماً إجتماعياً محدوداً ولكن في بعض الأحيان يستجيب للكبار المألوفين. ☐

ج. يظهر بعض الإهتمام، ويستجيب للاخرين، لكن لا يبادر بالتواصل الإجتماعي مع الكبار المألوفين. ☐

د. يظهر إهتماماً إجتماعياً واضحاً، يستجيب للاخرين، و أحياناً يبادر بالتواصل الإجتماعي مع الكبار المألوفين. ☐

هـ. يندمج في نطاق واسع من التفاعلات الإجتماعية التي تشتمل على الإستجابة والمبادرة بالتواصل الإجتماعي مع الكبار المألوفين. ☐

6. ما هو مستوى اندماج طفلك في التفاعلات الإجتماعية مع الأطفال الاخرين:-

أ. يظهر القليل أو عدم الإهتمام في التفاعلات الإجتماعية مع الأطفال الاخرين. ☐

ب. يظهر إهتماماً إجتماعياً محدوداً ولكنه أحيانا يستجيب لأطفال اخرين. ☐

ج. يظهر بعض الإهتمام، ويستجيب للاخرين، لكن لا يبادر بالتواصل الإجتماعي مع الأطفال الاخرين. ☐

د. يظهر إهتماماً إجتماعياً واضحاً، ويستجيب للاخرين، وأحياناً يبادر بالتواصل الإجتماعي مع الأطفال الاخرين. ☐

هـ. يندمج في نطاق واسع من التفاعلات الاجتماعية التي تشتمل على الإستجابة والمبادرة بالتواصل الإجتماعي مع الأطفال الاخرين. ☐

7. من فضلك اختر الوصف الأكثر دقة لمهارات طفلك في تناول الطعام:-

أ. يحتاج مساعدة كاملة أثناء تناول الطعام. ☐

ب. يأكل بأصابع يديه. ☐

ج يستطيع إستخدام الملعقة و لكن بفوضى. ☐

د. يستخدم ملعقة وشوكة. ☐

هـ. يأكل بشكل مستقل تماماً مع الإستخدام السليم لجميع أدوات المائدة. ☐

8. من فضلك اختر الوصف الأكثر دقة لمهارات طفلك في إستخدام الحمّام:-

أ. يرتدي حفاضات نهاراً وليلاً. ☐

ب. يرتدي حفاضات ولكن يشير و يطلب عندما يحتاج تغيير. ☐

ج. يشير أو يطلب الذهاب للحمّام ولكن لا يذهب بمفرده. ☐

د. مُدرّب على إستخدام الحمّام نهاراً (مع بعض الأخطاء) ، و قد يرتدي حفاضات ليلاً أو يخلعها. ☐

هـ. مُدرّب تماماً على إستخدام الحمّام ليلاً ونهاراً. ☐

9. من فضلك اختر الوصف الأكثر دقة لمهارات طفلك في إرتداء الملابس:-

أ. يحتاج الى مساعدة كاملة في إرتداء وخلع ملابسه. ☐

ب. يتعاون أثناء إرتداء ملابسه (مثل رفع ذراعيه). ☐

ج. يستطيع أن يقوم برفع أوسحب ملابسه. ☐

د. يستطيع أن يرتدي ملابسه بشكل جيد و لكن يحتاج مساعدة في عمل الأزرار و السحّاب ... الخ. ☐

هـ. يستطيع أن يرتدي و يخلع ملابسه بإعتماد كلي على نفسه. ☐

*Adrienne Perry, 2014

الجزء الثالث: إحتياجات أسرتك

في هذا الجزء نَودُّ أن نطرح عليك أسئلة حول إحتياجات أسرتك فيما يتعلق بالمعلومات و الدعم المطلوب لطفلك المُشخص باضطراب طيف التوحد. من فضلك إقرأ الفقرات بالأسفل و ضع اشارة ✓ تحت مستوى الدعم الذي تحتاجه أنت وأسرتك في كل من المجالات التالية.

المجالات	لا حاجة إلى أي دعم	الحاجة إلى القليل من الدعم	الحاجة إلى الكثير من الدعم
المعلومات 1. كيفية نمو وتطور الأطفال المُشخصين باضطراب طيف التوحد			
2. كيفية اللعب والتحدث مع طفلي المُشخص باضطراب طيف التوحد			
3. كيفية تعليم طفلي المُشخص باضطراب طيف التوحد			
4. كيفية التعامل مع سلوك طفلي المُشخص باضطراب طيف التوحد			
5. معلومات حول أي حالة أو إعاقة قد تكون موجودة لدى طفلي المُشخص باضطراب طيف التوحد			
6. معلومات حول الخدمات المتوفرة حالياً لطفلي المُشخص باضطراب طيف التوحد			

المجالات	**لا حاجة إلى أي دعم**	**الحاجة إلى القليل من الدعم**	**الحاجة إلى الكثير من الدعم**
7. معلومات عن الخدمات التي يمكن أن يتلقاها طفلي المُشخص باضطراب طيف التوحد في المستقبل			
الدعم الأسري والإجتماعي 1. التحدث مع فرد من أسرتي حول مايقلقني			
2. وجود أصدقاء أتحدث إليهم			
3. إيجاد المزيد من الوقت لنفسي			
4. مساعدة زوجي/ زوجتي تقبل أي حالة قد يصاب بها طفلنا المُشخص باضطراب طيف التوحد			
5. مساعدة أسرتنا مناقشة المشاكل والوصول إلى حلول			
6. مساعدة أسرتنا دعم بعضها البعض خلال الأوقات الصعبة			
7. تحديد من يقوم بالأعمال المنزلية ورعاية الأطفال وغيرها من المهام الأسرية			
8. إتخاذ القرارات بشأن الأنشطة الترفيهية العائلية والقيام بها			
الدعم المالي 1. دفع تكاليف مثل الطعام، السكن، الرعاية الطبية، الملابس، أو المواصلات			
2. الحصول على أي معدات خاصة يحتاجها طفلي			
3. دفع تكاليف العلاج أو الرعاية النهارية أو الخدمات الأخرى التي يحتاجها طفلي			
4. الإستشارات أو المساعدة في الحصول على عمل			
5. دفع تكاليف خدمة مجالسة الأطفال أو خدمة الرعاية المؤقتة			
6. دفع ثمن الألعاب التي يحتاجها طفلي			
الشرح للاخرين			

المجالات	لا حاجة إلى أي دعم	الحاجة إلى القليل من الدعم	الحاجة إلى الكثير من الدعم
1. شرح حالة طفلي لوالديّ او والديّ زوجي/زوجتي			
2. شرح حالة طفلي لأخوتة أو أخواتة			
3 . معرفة كيفية الرد على الأسئلة المتعلقة بطفلي المشخص بالتوحد من قبل الأصدقاء،أو الجيران،أو الغرباء.			
4. شرح حالة طفلي لأطفال اخرين			
5. العثور على مواد قراءة حول أسر أخرى لديها طفل مُشخص بإضطراب طيف التوحد مثل طفلي			
رعاية الطفل 1. إيجاد جلساء أطفال أو مقدمي خدمات الرعاية المؤقتة من لديهم الرغبة و القدرة على رعاية طفلي المُشخص باضطراب طيف التوحد			
2. إيجاد برنامج رعاية يومي أو روضة لطفلي المُشخص باضطراب طيف التوحد			
3. الحصول على الرعاية المناسبة لطفلي في المسجد أو الكنيسة أو المعبد أثناء تأدية الطقوس الدينية			
دعم من قبل الاخصائيين 1. الإجتماع مع إمام، كاهن، او حاخام			
2. الإجتماع مع مستشار (أخصائي نفسي، إجتماعي، طبيب نفسي)			
3.الحصول على المزيد من الوقت للتحدث مع معلم أو معالج طفلي			
خدمات المجتمع 1.الإلتقاء والتحدث مع أهالي أطفال مُشخصين باضطراب طيف التوحد تماثل حالتهم حالة طفلي			
2. إيجاد طبيب يفهمني و يفهم إحتياجات طفلي			
3. إيجاد طبيب الأسنان الذي سوف يتابع طفلي			

*Bailey et al, 1992

الجزء الرابع:والصعوبة القوة مواطن أستبيان SDQ للوالدين)سنة 17-4(

يرجى الاجابة على كل فقرة ب : غير صحيح، صحيح نوعا ما، أو صحيح بالتأكيد بوضع اشارة ✓ تحت الاجابة المناسبة. حاول أن تكون دقيقا في اجابتك. سوف يساعدنا كثيرا اذا أجبت على كل فقرة حتى و ان كنت غير متأكد أو ترى أنه غير مناسب. يرجى ان تكون اجابتك حول سلوك طفلك خلال الستة الأشهر الاخيرة.

	غير صحيح	صحيح نوعا ما	صحيح بالتأكيد
يهتم بمشاعر الآخرين			
لا يستطيع البقاء أو الاستقرار في مكان واحد. كثير الحركة			
كثيرا ما يشكو من صداع أو آلام في البطن أو الشعور بالغثيان			
يشرك الاخرين بسهولة فيما يخصه { لعب، أقلام، ألعاب، حلويات....الخ}			
كثيرا ماتنتابه نوبات من الغضب أو سريع الغضب			
يحب العزلة. يميل الى اللعب لوحده			
مطيع على وجه العموم. عادة يفعل ما يطلبه منه الكبار			
يقلق من أشياء كثيرة. كثيرا ما يبدو عليه القلق			
يساعد الاخرين اذا ما حدث لأحدهم مكروه			
يتململ أو يتلوى باستمرار { جسمه في حركة مستمرة }			
لديه على الأقل صديق واحد جيد			
كثيرا ما يتعارك مع الاخرين من نفس سنه أو يستأسد عليهم			
كثيرا ما يكون غير سعيد، حزين أو يبكي بسهولة			
في الغالب محبوب ممن هم في سنه			
يتشتت انتباهه بسرعه وقليل التركيز			
عصبي أو متشبث {متعلق} بالاخرين في المواقف الجديدة. من السهل أن يفقد ثقته فسه			
لطيف مع من هم أصغر منه			
كثيرا ما يكذب، يخدع أو يغش			
يستهزأ منه أو يستأسد عليه من هم في سنه			

كثيرا ما يتطوع لمساعدة الاخرين { الوالدين، المدرسين، الاطفال الاخرين}			
يفكر قبل أن يتصرف			
يسرق من البيت أو المدرسة أو من أماكن أخرى			
ينسجم بشكل أفضل مع الكبار عنه مع الأطفال في نفس سنه			
يخاف من أشياء كثيرة. من السهل تخويفه			
يتابع أداء الواجبات حتى النهاية. لديه انتباه جيد			

*Robert Goodman, 2005

الجزء الخامس: حالتك النفسية العامة

يرجى قراءة كل فقرة و اختيار الاجابة التي ترى أنها تمثل مشاعرك. لا تستغرق وقتا طويلا باختيار اجاباتك حيث أن اجابتك الفورية على كل فقرة ستكون على الارجح أكثر دقة. يرجى أن تكون اجابتك بناء على ما كنت تشعر به خلال الاسبوع الماضي على الاغلب.

1. اشعر بحالة توتر وضيق:

معظم الوقت	كثير من الوقت	احيانا	ابدا
☐	☐	☐	☐

2. ينتابني احساس مخيف وكأن شيئا سيئا على وشك الحدوث:

اكيد وبدرجة عالية	نعم لكن ليس بدرجة عالية	قليلا لكن لا يقلقني	أبدا
☐	☐	☐	☐

3. تراودني أفكار مقلقه:

معظم الوقت	كثير من الوقت	احيانا وليس كثيرا	قليلا جدا
☐	☐	☐	☐

4. أستطيع ان أشعر بالهدوء و الارتياح:

اكيد	عادة	ليس كثيرا	ابدا
☐	☐	☐	☐

5. أشعر بالوجس:

ابدا	احيانا	كثيرا	كثيرا جدا
☐	☐	☐	☐

6. اشعر باضطراب وعدم القدرة على الاستقرار في أي موضع:

بدرجة كبيره جدا	بدرجة كبيره	بدرجة قليله	ابدا
☐	☐	☐	☐

7. يراودني احساس بالرعب:

كثير جدا	كثيرا	قليلا	ابدا
☐	☐	☐	☐

8. مازلت استمتع بالأشياء التي كنت استمتع بها من قبل:

بنفس الدرجة تماما	بدرجة أقل	بدرجة قليلة	لا أستمتع بأي منها ابدا
☐	☐	☐	☐

9. أستطيع ان أضحك وأرى الفكاهة في الموقف:

تماما وبنفس القدر من قبل	بدرجة أقل	بدرجة قليلة ولكن ليس مثل ماكنت في الماضي	أبدا
☐	☐	☐	☐

10. اشعر بالمرح:

ابدا	قليلا	احيانا وليس كثيرا	معظم الوقت
☐	☐	☐	☐

11. اشعر وكأنني اصبحت بطيء الحركة:

معظم الوقت	كثير من الوقت	احيانا	ابدا
☐	☐	☐	☐

12. لم اعد أهتم بمظهري:

اكيد	لا أهتم بذلك كما يجب	لا أهتم بذلك	مازلت اهتم بمظهري كما كنت
☐	☐	☐	☐

13.اتوقع الأمور بالتفاؤل:

كما كنت دائما	اقل من السابق	اقل كثيرا	لا أتطلع الى ذلك نهائيا
☐	☐	☐	☐

14. أستطيع الاستمتاع بقراءة كتاب جيد او الاستماع الى الراديو او مشاهدة برنامج بالتلفزيون:

كثيرا	احيانا	قليلا	نادرا
☐	☐	☐	☐

*Zigmond and Snaith, 1983

نهاية الاستبانة

شكرا لك لإكمال الاستبانة

يرجى إعادة الاستبانة ونموذج الموافقة عالمشاركة بالدراسة باستخدام المغلف المدفوع مسبقا.

Appendix D: Participants information sheet (Arabic version)- Support needs of Arab families of children with ASD living in the UK

WARWICK
THE UNIVERSITY OF WARWICK

نموذج ورقة معلومات عن الدراسة

عنوان الدراسة: دراسة دعم احتياجات الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد الذين يعيشون في المملكة المتحدة.
أسماء الباحثين: براءه العلاوي وRichard Hastings (جامعة Warwick)

مقدمة

نوّد أن نشكرك لاهتمامك بالمشاركة في دراسة دعم احتياجات الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد. مشاركتك في هذه الدراسة ستكون لها مساهمة قيّمة بالنسبة لأبحاث الأسر العربية و ذوي الحاجات الخاصة في المملكة المتحدة. نتوقع أن تستغرق الاستبانة منك عشرين دقيقة تقريباً لإنهائها.

سيشترك في هذه الدراسة مقدمو الرعاية الأولية من الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد الذين تتراوح أعمارهم بين (أربعة أعوام و خمسة عشر عاماً و احد عشر شهراً) والذين يعيشون في المملكة المتحدة. مقدمو الرعاية الأولية قد لا يكونون أمهات الأطفال و لكن قد يكون شخصاً بالغاً يهتم بالطفل المُشخص باضطراب طيف التوحد أغلب الوقت. الأم قد تكون البيولوجية (المُنجبة) أو قد تكون من تَبنّت أو إحتضنت الطفل.

من فضلك اقرأ بعناية المعلومات التالية، من المهم أن تعرف ما الذي تتضمنه الدراسة. إذا كان هناك أي شيء غير واضح أو إذا رغبت بالحصول على أي معلومات إضافية من فضلك تواصل معنا عبر العناوين أدناه.

(الجزء الأول يشتمل على معلومات عن الهدف من الدراسة و ماذا سيحدث في حال شاركت بالدراسة. أما الجزء الثاني يزودك بمعلومات أكثر تفصيلاً حول كيفية إجراء الدراسة). يرجى الإحتفاظ بهذا النموذج للرجوع إليه في حال أردت أن تذكر نفسك بهذه الدراسة أو إذا أردت أن تتواصل معنا

<u>الجزء الأول</u>

ماهو موضوع الدراسة؟

سيتم إجراء هذه الدراسة للتعرف على الإحتياجات التي يمكن دعمها للأسر العربية ذوي الاطفال المُشخصين باضطراب طيف التوحد الذين يعيشون في المملكة المتحدة.

هل يتوجّب عليّ المشاركة في الدراسة؟

أنت غير مُجبر على المشاركة في هذه الدراسة، مشاركتك تطوعيه. يمكنك الإحتفاظ بورقة المعلومات هذه. في حال إخترت المشاركة في الدراسة سنطلب منك الموافقة على جميع البنود المرفقة في نموذج الموافقة على المشاركة في الدراسة. يرجى العلم بأنه لا يمكنك سحب نموذج الإستبانة بعد الإجابة عليه وتسليمه لفريق الدراسة، و ذلك لأن الإستبانة لا تحتوي أسماء أو
معلومات شخصية تتيح لفريق الدراسة التعرف على إستبانتك التي أكملتها.

ما الذي سيحدث اذا شاركت في الدراسة؟

بمجرد أن تقرأ ورقة المعلومات هذه، سوف يُطلب منك أن تقرأ البنود الموجودة في نموذج الموافقة على المشاركة بالدراسة والإشارة إلى موافقتك على كل واحد منها. نريد أن نتأكد إذا كنت توافق على المشاركة بالدراسة. سيكون هناك استبانة إلكترونية أو بريدية مجهولة الإسم (سيتم توفير أظرف بريدية مدفوعة مسبقاً لمن يرغبون في المشاركة عبر البريد). تحتوي الاستبانة على أسئلة عنك وعن أسرتك، و احتياجاتك كأحد الوالدين العرب، و طفلك المُشخص باضطراب طيف التوحد. ستكون الاستبانة متوفرة باللغة العربية و الإنجليزية بناءً على ماتفضله تختار. نتوقع أن تأخذ منك الاستبانة مايقارب عشرين دقيقة لإنهائها.

ما هي السلبيات و/أو الآثار المرافقة و/أو المخاطر و/أو المشقات التي قد تترتب على المشاركة في هذه الدراسة؟

لا نتوقع ان يكون هنالك أي سلبيات أو مخاطر قد تترتب على المشاركة في الدراسة. الأسئلة التي نطرحها سبق و أن طُرحت من قبل في دراسات سابقة. من الممكن أن تجد بعض الأسئلة مزعجة و ذلك لأننا نسأل عن صعوبات تُواجهها أنت و أسرتك و طفلك المُشخص بإضطراب طيف التوحد. إذا وجدت نفسك منزعجاً من أي سؤال فأنت غير مُجبر على الإجابة وغير مُجبر على إكمال الاستبانة.

إذا وجدت أسئلة الدراسة تعنيك أنت أو طفلك المُشخص باضطراب طيف التوحد، فمصادر المعلومات و الدعم التالية قد تكون مفيدة لكم:

1. موقع دائرة الصحة الوطنية NHS ، يمكن أن تجد معلومات بخصوص خدمات الدعم العاطفي لمقدمي الرعاية في منطقتك.
http://www.nhs.uk/ServiceSearch/Carers%20emotional%20support%20services/LocationSearch/374
2. التواصل مع طبيبك العام، فهو قادر على فحص أي عوامل تؤثر على صحتك وسيقدم الدعم المصمم خصيصاً لحالتك.
3. موقع مقدمي الرعاية في المملكة المتحدة الموجود بالأسفل. يقدم لك معلومات عن كيفية الحصول على تقييم لمقدمي الرعاية في إنجلترا، شمال ايرلندا، إسكوتلند ، و ويلز. بالإضافة إلى معلومات مُوسّعة حول أنواع الدعم الذي تتطلع إليه.
http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment

ماهي الفوائد المتوقعة من المشاركة في هذه الدراسة؟

مشاركتك في هذه الدراسة تتيح لنا فرصة أكبر للتعرف على الدعم الذي تحتاجه أنت وأسرتك للعناية بطفلك المُشخص باضطراب طيف التوحد في المملكة المتحدة. المعلومات التي تزودنا بها ستساعدنا على فهم الأسر العربية, مثل أسرتك, و مشاركة مثل هذه المعلومات على نطاق واسع وبالتالي إطلاعنا على طرق لدعم احتياجات الأسر العربية التي لديها أطفال مشخصين باضطراب طيف التوحد و الذين يعيشون في المملكة المتحدة.

النفقات و المدفوعات

نحن لن نقدم لك عوضاً عن المشاركة في الدراسة، كما أنه لن يكون هنالك أي نفقات تترتب عليك أو على طفلك مقابل مشاركتك في هذه الدراسة.

ما الذي سيحدث عند إنتهاء الدراسة؟

عند إنتهاء الدراسة سيتم تخزين النماذج و الاستبانة من قبل جامعة وريك في صيغة غير معروفة (مجهولة الإسم). كل البيانات سوف تُحفظ بطريقة آمنة مدة لا تقل عن عشر سنوات، وذلك وفقاً لسياسة إدارة بيانات البحث في جامعة وريك في ملف إلكتروني سري يتم فتحه بموجب كلمة مرور فقط من قبل فريق الدراسة.
سنقوم بنشر تقارير و تقديم عروض حول نتائج الدراسة. يرجى العلم بأنه لا يمكن تحديد هويتك أنت و طفلك و ذلك لأن الإستبانة مجهولة الإسم. البحث في هذه الدراسة يأتي إستكمالاً لدرجة الدكتوراة للباحث الرئيسي.

هل ستُحفظ مشاركتي في الدراسة بشكل سريّ؟

نعم، سنتبع ممارسات أخلاقية و قانونية صارمة حيث أن كل البيانات المتعلقة بك ستُعامل بسريّة. تفاصيل أكثر يمكن أن تجدها في الجزء الثاني من هذه الورقة.

ماذا إذا كان هنالك مشكلة ما؟

أي شكوى بخصوص الطريقة التي عوملت بها أثناء الدراسة أو أي ضرر مُحتمل قد يحصل لك سيتم النظر فيه. تفاصيل أكثر موجودة في الجزء الثاني من هذه الورقة.

نهاية الجزء الأول.

إذا كانت المعلومات المقدمة في الجزء الأول قد أثارت إهتمامك و أردت المشاركة، من فضلك اقرأ الجزء الثاني قبل إتخاذ أي قرار.

الجزء الثاني

من المسؤول عن تنظيم و دعم هذه الدراسة؟

جامعة وريك مسوؤلة عن هذه الدراسة. الدراسة تتلقى تمويلاً من قبل جامعة مؤتة في الأردن وهي الداعمة للباحث الرئيسي لتكملة متطلبات درجة الدكتوراة في جامعة وريك.

ماذا سيحدث إذا لم أرغب بالإستمرار في المشاركة بهذه الدراسة؟

أنت غير مُجبر على المشاركة في هذه الدراسة، مشاركتك تطوعيه. في حال اخترت المشاركة في الدراسة سنطلب منك الموافقة على جميع البنود المرفقة في نموذج الموافقة على المشاركة في الدراسة. يُرجى العلم بأنه لا يمكنك سحب نموذج الاستبانة بعد الإجابة عليه وتسليمه لفريق الدراسة، و ذلك لأن الاستبانة لا تحتوي على أسماء أو معلومات شخصية تتيح لفريق الدراسة التعرف على استبانتك التي أكملتها.

مع من يمكن أن أتواصل في حال رغبت بأن أتقدم بشكوى؟

أي شكوى مقدمة منك حول طريقة التعامل معك أثناء الدراسة أو أي ضرر مُحتمل قد يحصل لك سيتم النظر فيه. من فضلك قم بإرسال الشكوى إلى الشخص المذكور أدناه. و هو أحد كبار المسؤولين في جامعة وريك و هو مستقل تماما عن الدراسة الحالية:

Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

هل ستُحفظ مشاركتي بشكل سريّ؟

كما ذُكر سابقاً بيانات الاستبانة مجهولة الإسم و ستُحفظ بشكل آمن مدة لا تقل عن عشر سنوات وفقاً لسياسة إدارة بيانات البحث في جامعة وريك في ملف إلكتروني سريّ يتم فتحه بموجب كلمة مرور فقط من قبل فريق الدراسة. سيتم التخلص نهائياً من البيانات وفقاً لإجراءات الجامعة في ذلك الوقت.

ماذا سيحدث لنتائج الدراسة؟

نتائج الدراسة سيتم مشاركتها مع المدارس و الجمعيات الخيرية التي شاركت في الدراسة. سيتم تشجيع المدارس و الجمعيات على إيصال النتائج إلى أولياء الأمور. كما يمكن أن تُستخدم النتائج أيضاً بشكل مجهول الإسم في المؤتمرات والمجلات العلمية و ذلك لمساعدة الباحثين على زيادة فهم احتياجات الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد.

من قام بمراجعة هذه الدراسة؟

تم مراجعة هذه الدراسة وحصولها على موافقة بتاريخ (20 نيسان 2017 رقم70/16-17) من قبل لجنة أخلاقيات البحث العلمي في مجال العلوم الإنسانية والإجتماعية.

ماذا إذا أردت معلومات أكثر حول الدراسة؟

إذا كان لديك أي أسئلة حول أي جانب من جوانب الدراسة، أو حول مشاركتك فيها، و لم يتم إجابتها في ورقة المعلومات هذه، يمكنك التواصل مع:

الباحث الرئيسي- : براءة العلاوي, جامعة وريك B.Alallawi@warwick.ac.uk
مشرف البحث- Richard Hastings, جامعة وريك R.Hastings@warwick.ac.uk

شكراً جزيلاً للوقت الذي منحته لقراءة ورقة معلومات الدراسة

Appendix E: Consent form (Arabic version)- Support needs of Arab families of children with ASD living in the UK

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دراسة دعم احتياجات الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف بالتوحد الذين يعيشون في المملكة المتحدة.

نموذج الموافقة على المشاركة في الدراسة

من فضلك اقرأ بعناية العبارات الموضحة أدناه، و إذا تم الموافقة على ما هو منصوص ضع لكل عبارةX

في حال عدم موافقتك على كل العبارات المذكورة فإنه للأسف لا يمكننا الاستفادة من اجابتك على الاستبانة.

☐ 1. أؤكد بأنني قرأت وفهمت نموذج ورقة المعلومات المُزوّد حول الدراسة أعلاه. ولقد أتيحت لي الفرصة للإطلاع على المعلومات وطرح الأسئلة والحصول على إجابات وافية.

☐ 2. أدرك أن مشاركتي في هذه الدراسة تطوعية.

☐ 3. أدرك أنه في حال حصل فريق الدراسة على إجاباتي على الإستبانة لا يمكنني سحب بياناتي من الدراسة و ذلك لأن الاستبانة مجهولة الإسم.

☐ 4. أدرك أن بياناتي سيتم تخزينها بشكل آمن مدة لا تقل عن عشر سنوات و ذلك وفقا لسياسة إدارة بيانات البحث في جامعة وريك.

☐ 5. أوافق على المشاركة في الدراسة أعلاه.

Appendix F: Ethics approval- support needs of Arab families of children with ASD living in the UK

Thursday, 20 April 2017

Professor Richard Hastings

CEDAR
University of Warwick Coventry
CV4 7AL

Dear Professor Hastings,

Ethical Application Reference: 70/16-17
Title: Support Needs of Arab Families of Children with Autism, Living in the UK: A survey

Thank you for submitting your ethics application to the Humanities and Social Sciences Research Ethics Sub-Committee for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full approval for your project is hereby granted.

Before conducting your research it is strongly recommended that you complete the on-line ethics course:

https://www2.warwick.ac.uk/services/ldc/researchers/opportunities/development_support/research_integrity/

Support is available from your Departmental contact in Research & Impact Services

Any material changes to any aspect of the project will require further consideration by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

Dr. F. Schlaghecken

Dr Friederike Schlaghecken
Chair, Humanities and Social Sciences Research Ethics Sub-Committee

Appendix G: Recruitment flyer- Support need of Arab families of children with ASD living in the UK

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Support needs study of Arab families of children with autism living in the UK

Are you a primary caregiver of a children with autism aged between 4 years and 15 years11 months from an Arab family, living in the UK? (Primary parental caregivers might not be the child's mother, but would be the adult who cares for the child with autism for most of the time. Mothers may also be biological, adoptive, or foster mothers).
Please take part in our new research study. We would be very keen to hear from you.

The research team at the University of Warwick wishes to explore support needs of Arab families who have a child with autism in the UK.

This research will further our understanding of your support needs as Arab caregivers of a child with autism in the UK, and (we hope) will help shape future support for Arab families and children.

To take part please go to our online survey or request a paper survey to be sent out to you.

If you have any questions or would like to know more about the study, please contact the main researcher by email: B.Alallawi@warwick.ac.uk or telephone: 024 7652 3638

Appendix H: Recruitment flyer (Arabic version)- Support need of Arab families of children with ASD living in the UK

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دراسة دعم احتياجات الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد الذين يعيشون في المملكة المتحدة

هل أنت من مقدمي الرعاية الأوليّة من الأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد الذين تتراوح أعمارهم بين (أربعة أعوام و خمسة عشر عاما و احد عشر شهراً) والذين يعيشون في المملكة المتحدة؟ (مقدمو الرعاية الأوليّة قد لا يكونون أمهات الأطفال و لكن قد يكون شخصاً بالغاً يهتم بالطفل المُشخص باضطراب طيف التوحد أغلب الوقت. الأم قد تكون البيولوجية (المُنجبة) أو قد تكون من تَبنّت أو إحتضنت الطفل المُشخص باضطراب طيف التوحد).

نودّ من فضلك المشاركة في هذه الدراسة البحثية الجديدة. سنكون حريصين جداً أن نسمع منك.

يتطلع فريق البحث في جامعة وريك إلى التعرف على الاحتياجات التي يمكن دعمها للأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد والذين يعيشون في المملكة المتحدة.

هذا البحث سوف يُعزّز فهمنا حول دعم احتياجاتك كأحد مقدمي الرعاية الأوليّة من الأسر العربية ذوي طفل مُشخص باضطراب طيف التوحد في المملكة المتحدة، وبالتالي المساعدة في تشكيل الدعم المستقبلي للأسر العربية ذوي الأطفال المُشخصين باضطراب طيف التوحد.

للمشاركة في الدراسة يُرجى الدخول إلى الاستبانة عبر الإنترنت:

https://www.snapsurveys.com/wh/s.asp?k=151058906611

أو طلب استبانة ورقيّة عبر البريد ليتم إرسالها إليك:

https://warwick.ac.uk/fac/soc/cedar/surveysupportarabic/arabicpaperrequest/

إذا كان لديك أي أسئلة أو ترغب في معرفة المزيد عن الدراسة، يرجى الإتصال بالباحث الرئيسي عن طريق البريد الإلكتروني: **B.Alallawi@warwick.ac.uk** أو الهاتف **024 76523638**

Appendix I: Recruitment email- Support need of Arab families of children with ASD living in the UK

Dear Sir / Madam,

I hope this email finds you well. I am a doctoral researcher from the university of Warwick. I am working with professor. Richard Hastings on a research study that aims to explore support needs of Arab families of children with Autism. This is the first study in the UK that focuses on this area of research.

This research study has a scientific benefit as understanding Arab family's needs when raising a child with autism and living in the UK will help schools, professionals, and researchers understand this group more, and essentially, help to support them in the most appropriate and effective ways.

We have designed an anonymous survey that can be completed online or by post (prepaid envelops will be provided for participants who wish to take part through a postal survey). The survey is available in English or Arabic, depending on participants preferences. The survey will take around 20 minutes to complete.

Parents' responses to this survey will make their voice heard and help us to understand more about Arab families like theirs, to share this information widely, and to inform ways to better support Arab families of children with autism in the UK.

Families can be encouraged to take part in the **online survey** by following these links:
English online version: https://www.snapsurveys.com/wh/s.asp?k=151024584250
Arabic online version: https://www. snapsurveys.com/wh/s.asp?k=151058906611

A **paper copy of the survey** to be sent to parents who request a survey via the following links:

English paper survey:
https://warwick.ac.uk/fac/soc/cedar/surveysupportarabic/englishpaperrequest/

Arabic paper survey:
https://warwick.ac.uk/fac/soc/cedar/surveysupportarabic/arabicpaperrequest/

We greatly appreciate it if you could promote and share the survey information to suitable families. I have also attached copies of the short recruitment flyers that can be sent/given to potentially interested families.

If you have any questions or would like to know more about the study, please feel free to contact me at: **B.Alallawi@warwick.ac.uk** or telephone: **07459824593**.

Thank you very much for your time and cooperation.

Appendix J: Reminder email- Support need of Arab families of children with ASD living in the UK

Reminder: Survey of support needs of Arab families of children with autism in the UK.

Dear Sir / Madam,

We sent the below email to you asking you to assist us in sending/ giving short recruitment flyers to families of children with autism from an Arab background. In case it is easier for you to give out hard copies to families, I have sent by post to you a survey pack for at least five families (prepaid envelopes are also provided). We would greatly appreciate it if you could give the hard copies of the information and survey to families and encourage them to complete the survey.

Please let me know if you need more copies of the information/survey to give to families.

Your cooperation is much appreciated as it will help us understand this group more, and essentially, help to support them in the most appropriate and effective ways.

If you have any questions, please feel free to contact me at:
B.Alallawi@warwick.ac.uk or telephone: **07459824593**.

Appendix K: Reminder email before closing the survey- Support need of Arab families of children with ASD living in the UK

Reminder: Survey of support needs of Arab families of children with autism in the UK- IMPORTANT

Dear Sir / Madam,

I hope this email finds you well. We contacted you previously to ask you to assist us in distributing our survey to families of children with autism from an Arab background. This is a unique piece of research seeking to understand for the first time the support needs of Arab families of children with autism living in the UK.

The deadline for completing the survey is **30th of November 2018**. We would greatly appreciate it if you could promote and share the below survey links to suitable families (the survey is available in English and Arabic depending on participants' preferences).

English version: https://www.snapsurveys.com/wh/s.asp?k=151024584250
Arabic version: https://www. snapsurveys.com/wh/s.asp?k=151058906611

Please let us know if you would like me to re send hard copies of the survey to give to families (prepaid envelopes are provided). Completed surveys can then be posted in a standard post box, families do not have to take it to the post office.

If you have any questions, please feel free to contact me at:
B.Alallawi@warwick.ac.uk or telephone: **07459824593**.

Appendix L: Participants information sheet (English version)- Support needs of Arab families of children with ASD living in the UK

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PARTICIPANT INFORMATION SHEET

Study Title:	Support needs of Arab families of children with autism living in the UK: A survey
Investigator(s):	Barah Alallawi and Richard Hastings (University of Warwick)

Introduction

Thank you for your interest in taking part in the support needs of Arab families' study. Your participation in this study will make a valuable contribution to UK based Arab family and disability research. We estimate that the survey will take around <u>20 minutes</u> for you to complete.

Arab Primary caregivers of children with autism who are aged between 4 years and 15 years 11 months from Arab families, living in the UK, will be recruited. Primary parental caregivers might not be the child's mother, but would be the adult who cares for the child with autism for most of the time. Mothers may be biological, adoptive, or foster mothers.

Please take time to read the following information carefully. It is important for you to understand what the research would involve. If there is anything that is unclear, or if you would like more information please contact us using the details provided at the end.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study). Please keep this information sheet to refer to in case you want to remind yourself about this research or make contact with us.

PART 1

What is the study about?

This study will be conducted to identify the support needs of Arab families of children with autism living in the UK.

Do I have to take part?

You are under no obligation to participate in the research, your involvement is voluntary. You can keep this information sheet. If you choose to participate, we will ask you to complete some consent statements to confirm that you have agreed to take part. However, you will not be able to withdraw from the research after the research team has received your completed survey questionnaire. This is because there will be no name or other identifying information on the survey, so the research team will not be able to identify your survey.

What will happen to me if I take part?

Once you have read this study information, you will be asked to read some statements and to indicate your agreement to each one. We need to check that you agree to participate in the research. The anonymised online/postal survey (prepaid envelopes will be provided for participants who wish to take part through a postal survey) then includes questions asking about you and your family, your needs as an Arab parent and about your child with autism. The survey will be available for completion in English or Arabic, depending on your preferences. We expect the survey to take part about 20 minutes to complete in total.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

We do not anticipate any disadvantages or risks associated with taking part in this research. The questions that we are asking have been used in several research studies before. However, it is possible that you will find some of the questions to be upsetting because we do ask about some of the difficulties faced by you, your family, and your child with autism. If you are upset by any of the questions, you do not have to respond to them and you are under no obligation to continue with the survey.

If the survey questions make you concerned about yourself or your child with autism, the following sources of information and support may be helpful for you:

1- The NHS website. You can find out about any emotional support services for carers in your area.

http://www.nhs.uk/ServiceSearch/Carers%20emotional%20support%20services/LocationSearch/374
2- Contacting your GP. They will be able to look at any factors affecting your wellbeing and offer tailored support.

3- The Carers UK website below. It provides information about how to get a carers' assessment in England, Northern Ireland, Scotland and Wales and in-depth information about the types of support that you can expect:
http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment

What are the possible benefits of taking part in this study?

Involvement in this research provides an opportunity to tell us about some of the support needs that you and your family have caring for a child with autism in the UK. The information you provide will help us to understand more about Arab families like yours, to share this information widely, and to inform ways to better support Arab families of children with autism living in the UK.

Expenses and payments

We will not be offering payments for taking part in this study. Taking part in this study will incur no expenses for you or your child.

What will happen when the study ends?

At the end of the study, the survey and forms will be stored by the University of Warwick in an anonymised format. The data will then be securely stored for a minimum of 10 years, in line with University of Warwick policy on secure university servers in a password protected computer file which only the researchers will have access to.

We will publish reports and give presentations about the results of the study. Because the survey is anonymous, you or your child will not be able to be identified in any way. This study research is contributing to the primary researcher's PhD.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

The University of Warwick is responsible for this research. The research has received funding from Mutah University – Jordan who are supporting Barah Alallawi's PhD studies at the University of Warwick.

What will happen if I don't want to carry on being part of the study?

You are under no obligation to participate in the research, your involvement is voluntary. If you choose to participate, we will ask you to complete some consent statements to confirm that you have agreed to take part. However, you will not be able to withdraw from the research after the research team has received your completed survey questionnaire. This is because there will be no name or other identifying information on the survey, so the research team will not be able to identify your survey.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Will my taking part be kept confidential?

The anonymised survey data will be securely stored for a minimum of 10 years, in line with University of Warwick policy on secure university servers in a password protected computer file. Data will be destroyed in accordance with the University's procedures at that time. Access is restricted to the research team.

What will happen to the results of the study?

Findings of the research will be shared with schools and charities that take part. The schools and charities will also be encouraged to pass on this information to parents. The findings may also be used anonymously in academic conferences and publications to help researchers further understand this group of families.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC): 70/16-17

What if I want more information about the study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact: Primary researcher– Barah Alallawi, University of Warwick, B.Alallawi@Warwick.ac.uk Research supervisor- Richard Hastings, University of Warwick, R.Hastings@Warwick.ac.uk

Thank you for taking the time to read this Participant Information Sheet.

Appendix M: Consent form (English version)- Support needs of Arab families of children with ASD living in the UK

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CONSENT FORM

Title of Project: Support needs of Arab families of children with autism, living in the UK: A survey.

Name of researcher(s): Barah Alallawi (University of Warwick) and Richard Hastings (University of Warwick).

Please read carefully the initial statements below. If you agree with these statements, then tick in the corresponding box. **Unfortunately, if you do not consent to all of the statements, we cannot use your survey responses.**

1. I confirm that I have read and understood the information sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary. ☐

3. I understand that once the survey has been received by the research team, I will not be able to withdraw my data from the research study as the survey is anonymous. ☐

4. I understand that my data will be securely stored for a minimum of 10 years, in line with the University of Warwick's Research Data Management Policy. ☐

5. I agree to take part in the above study ☐

Appendix N: Participants information sheet (Somali version)- Support needs of Arab families of children with ASD living in the UK

XAASHIDA MACLUUMAADKA KA QAYBQAATAHA FOOL KA FOOL SAHAMINTA KU BUUXINAYA

Magaca Daraasadda:	Baahiyaha taageerada qoysaska Carabta ah ee carruurta qabta cudurka dhakaakaha (autism) ee Ingiriiska ku nool: Sahamin
Baaraha(reyaasha):	Barah Alallawi iyo Richard Hastings (jaamacadda University of Warwick)

Horudhac

Waxaa adiga laguugu baaqayaa in aad ka qayb qaadato daraasad cilmibaaris. Ka qaybqaadashada aad kaga qayb qaadato daraasaddani waxay caawin doontaa in la fahmo waayo aragnimada aad ka haysato ama waxyaabaha aad kala kulantay soo korinta ilme qaba cudurka dhakaakaha. Waxaan aad u rabnaa in aan adiga kaa war helno. Ka hor inta aadan go'aan gaarin, fadlan waqti u qaado si aad macluumaadka soo socda taxaddar ugu akhrisato. Waxaa muhiim ah in aad fahanto waxa ay cilmibaaristu ka koobnaan doonto. Dadka kale daraasadda kala hadal haddii aad rabto.

(Qaybta 1 waxaa laguugu sheegayaa ujeeddada daraasadda iyo waxa adiga lagugu samayn doono haddii aad ka qayb qaadato. Qaybta 2 waxaa laguugu sii faahfaahinayaa macluumaadka ku saabsan fulinta daraasadda)

Fadlan annaga na weydii haddii aadan wax hubin ama haddii aad macluumaad dheeraad ah rabto. Waqti u qaado si aad uga go'aan gaarto haddii aad rabto in aad ka qayb qaadato iyo haddii kale.

QAYBTA 1

Maxay daraasaddu ku saabsan tahay?

Daraasaddan waxaa ujeeddo u ah in lagu soo ogaado baahiyaha taageerada qoysaska Carabta ah ee carruurta qabta cudurka dhakaakaha ee Ingiriiska ku nool.
Waxaa laga qayb gelin doonaa daryeel bixiyeyaasha ugu muhiimsan ee carruurta qabta cudurka dhakaakaha ee da'doodu u dhexeyso 4 sano iyo 15 sano iyo 11 bilood oo ka soo jeeda qoysas

Carab ah, oo Ingiriiska ku nool. Waxaa laga yaabaa in daryeel bixiyeyaasha ugu muhiimsan ee waalidka ah aanay ahayn ilmaha hooyadiis laakiin waxay noqonayaan qofka qaangaarka ah ee waqtiga ugu badan daryeela ama haya ilmaha qaba cudurka dhakaakaha. Hooyooyinku waxay noqon karaan hooyooyinka rumaad, kuwa ilmaha korsada, ama kuwa ilmaha koriya.

Qoysaska waxaa loo tixgelin karaa in ay yihiin Carab haddii ay asal ahaan ka soo jeedaan mid ka mid ah 22ka dal ee Jaamacadda Carabta ee soo socda (Aljeeriya, Soomaaliya, Masar, Libiya, Sudaan, Tunisiya, Moroko, Mauritaniya, Jabuuti, Baxrain, Isutagga Imaraadka Carabta, Cumaan, Kuwait, Qatar, Sacuudi Carabiya, Yaman, Urdun, Suuriya, Ciraaq, Dalka Falastiin, Libnaan, iyo Komoros).

Miyay aniga waajib ama khasab igu tahay in aan ka qayb qaato?

Adiga waajib kuguma aha in aad cilmibaarista ka qayb qaadato, ka qaybqaadashada ikhiyaar ayaad u leedahay. Waxaad haysan kartaa xaashidan macluumaadka. Haddii aad doorato in aad ka qayb qaadato, waxaan annagu ku weydiin doonnaa in aad buuxiso bayaanno oggolaansho si aad u xaqiijiso in aad oggolaatay in aad ka qayb qaadato. Hase yeeshee, adiga suurogal kuuma noqon doonto in aad cilmibaarista ka baxdo ka dib marka kooxda cilmibaaristu ay helaan xogwaraysiga sahaminta ee aad soo buuxisay. Waxay sidaas ku tahay maadaama aanay sahaminta ku qornayn magac ama macluumaad kaloo dadka lagu garto, markaa kooxda cilmibaaristu ma soo heli karaan sahamintaada.

Maxaa aniga la igu samayn doonaa haddii aan ka qayb qaato?

Ka dib marka aad akhriso macluumaadkan daraasadda ku saabsan, waxaa lagu weydiin doonaa in aad bayaanno akhriso oo aad tilmaanto in aad mid kaste waafaqsan tahay. Waxaan annagu u baahan nahay in aan hubinno in aad oggoshahay in aad cilmibaarista ka qayb qaadato. Sahaminta aanan magac lahayn ee fool ka foolka ah waxaa markaa ku jiri doona su'aalo idinku saabsan adiga iyo qoyskaaga, baahiyaha aad qabto adigoo ah waalid Carab ah iyo kuwo ku saabsan ilmahaaga qaba cudurka dhakaakaha. Cilmibaare ayaa su'aalaha adiga kuu akhrin doona waxuuna nuqulka sahaminta ku diiwaangelin doonaa jawaabaha aad bixiso. Waxaan filanaynaa in sahamintu ay qaadan doonto qiyaas ahaan 20 daqiiqo si loo buuxiyo.

Waa maxay khasaaraha, dhibaatooyinka soo raaca, halisaha, iyo/ama raaxo darrada suurogal ah in ay ka yimaaddaan ka qaybqaadashada daraasaddan?

Annagu ma saadaalinayno khasaare ama haliso soo raaca ka qaybqaadashada cilmibaaristan. Su'aalaha aan ku weydiinayno waxaa hore loogu isticmaalay dhowr daraasado oo cilmibaaris. Hase yeeshee, waxaa suurogal ah in aad ka xumaato qaar ka mid ah su'aalaha aan ku weydiinno maxaa yeelay waxaan fool ka fool kaaga waraysanaynaa qaar ka mid ah dhibaatooyinka idinku wajahan adiga, qoyskaaga, iyo ilmahaaga qaba cudurka dhakaakaha. Haddii aad ka xumaato qaar ka mid ah su'aalaha, khasab kuguma aha in aad kuwaas ka jawaabto oo waajib kuguma aha in aad sahaminta sii waddo.

Haddii su'aalaha sahamintu ay walaac kaaga keenaan adiga laftigaaga ama ilmahaaga qaba cudurka dhakaakaha, ilaha macluumaadka iyo taageerada ee soo socda ayaa waxtar kuu yeelan kara:

1- Barta internetka adeegga caafimaadka qaran ee NHS. Waxaad war ka heli kartaa adeegyada taageerada shucuureed ee daryeeleyaasha uga diyaar ah xaafaddaada.
http://www.nhs.uk/ServiceSearch/Carers%20emotional%20support%20services/LocationSearch/374
2- La xiriiridda Takhtarkaaga Guud (GP). Waxuu baari karaa arrimaha saamaynaya wanaagqabkaaga waxuuna kuugu deeqi karaa taageero kugu toosan.
3- Barta internetka ururka Carers UK (Daryeeleyaasha Ingiriiska) ee hoos ku taalla. Waxaa laga helaa macluumaad ku saabsan sida qiimaynta daryeeleyaasha looga helo England, Waqooyiga Ayrland, Skotland iyo Wales iyo macluumaad qotodheer oo ku saabsan noocyada taageerada ee aad filan karto:

http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment

Waa maxay faa'iidooyinka suurogal ah ee ku jira ka qaybqaadashada daraasaddan?

Ka qaybgalka daraasaddani waxay fursad kuu siinaysaa in aad annaga noo sheegto qaar ka mid ah baahiyaha taageerada ee adiga iyo qoyskaagu aad ka qabtaan daryeelidda ilme qaba cudurka dhakaakaha oo Ingiriiska ku nool. Macluumaadka aad bixiso waxay annaga naga caawin doonaan in aan fahan dheeraad ah ka helno qoysaska sidiina Carabta u ah, in aan macluumaadkan la wadaagno dad tiro badan, iyo in aan ku hagno siyaabaha ka fiican ee lagu taageeri karo qoysaska Carabta ah ee haysta carruur qabta cudurka dhakaakaha ee Ingiriiska ku nool.

Kharashyada iyo lacagaha la bixiyo

Annagu lacag kama bixin doonno ka qaybqaadashada daraasaddan. Ka qaybqaadashada daraasaddani kharash ma idiin keeni doonto adiga ama ilmahaaga.

Maxaa dhici doona marka daraasaddu dhammaato?

Dhammaadka daraasadda, jaamacadda University of Warwick ayaa sahaminta iyo foomamka ku kaydin doonta qaab aanan magac lahayn. Waxaa xogta markaa si adag loo kaydin doonaa muddo 10 sano ah, taasoo ku toosan siyaasadda jaamacadda University of Warwick uga taalla seerferrada jaamacadda ee amni leh iyadoo lagu hayn doono fayl kumbiyuutar oo erey isgarad lagu xiray kaasoo ay cilmibaareyaashu keligood arki karaan.
Natiijooyinka daraasadda waxaan ka soo saari doonnaa warbixinno waxaanan ka bixin doonnaa bandhigyo. Maadaama ay sahamintu tahay mid aanan magac lahayn, ma jiro hab

adiga ama ilmahaaga la idiin garan karo. Cilmibaaristan daraasaddu waxay qayb ka noqonaysaa shahaadada jaamacadda ee PhD ee cilmibaaraha ugu muhiimsan.

Miyaa sir lagu hayn doonaa ka qaybqaadashadayda?

Haa. Waxaan annagu fulin doonnaa habdhaqan anshaxa iyo sharciga si adag ugu toosan waxaana macluumaadka adiga kugu saabsan dhammaantood lagu hayn doonaa sir. Faahfaahin dheeraad ah waxaa lagu daray Qaybta 2.

Haddii dhibaato timaaddana?

Waxaa wax laga qaban doonaa cabasho kaste oo ku saabsan habka adiga laguula dhaqmay muddada daraasadda ama wixii waxyeello ah ee suurogal ah in ay ku gaarto. Macluumaadka faahfaahsan ee taas ku saabsan waxaa lagu bixiyey Qaybta 2.

Waxaa intaas ku dhan Qaybta 1.
Haddii macluumaadka Qaybta 1 ku jira ay ku xiise geliyeen oo aad ku fikirayso in aad ka qayb qaadato, fadlan akhriso macluumaadka dheeraadka ah ee Qaybta 2 ku jira ka hor inta aadan go'aan qaadanin.

QAYBTA 2

Yaa daraasadda habaynaya oo maal gelinaya?

Jaamacadda University of Warwick ayaa cilmibaaristan masuul ka ah. Waxaa cilmibaarista maalgelin laga siiyey jaamacadda Mutah University – Urdun oo taageeraysa duruusta shahaadada PhD ee Barah Alallawi uga socota jaamacadda University of Warwick.

Maxaa dhici doona haddii aanan anigu rabin in aan daraasadda ku sii jiro?

Adiga waajib kuguma aha in aad cilmibaarista ka qayb qaadato, ka qaybqaadashada ikhiyaar ayaad u leedahay. Haddii aad doorato in aad ka qayb qaadato, waxaan annagu ku weydiin doonnaa in aad buuxiso bayaanno oggolaansho si aad u xaqiijiso in aad oggolaatay in aad ka qayb qaadato. Hase yeeshee, adiga suurogal kuuma noqon doonto in aad cilmibaarista ka baxdo ka dib marka kooxda cilmibaaristu ay helaan xogwaraysiga sahaminta ee aad soo buuxisay. Waxay sidaas ku tahay maadaama aanay sahaminta ku qornayn magac ama macluumaad kaloo dadka lagu garto, markaa kooxda cilmibaaristu ma soo heli karaan sahamintaada.

Yaan la xiriiri karaa haddii aan rabo in aan cabasho diro?

Waxaa wax laga qaban doonaa cabasho kaste oo ku saabsan habka adiga laguula dhaqmay muddada daraasadda ama wixii waxyeello ah ee suurogal ah in ay ku gaartay. Fadlan cabashadaada ku hagaaji qofka halkan hoose ku qoran, oo ah sarkaal sare oo ka mid ah jaamacadda University of Warwick qofkaas oo gebi ahaan daraasaddan ka madaxbannaan:

Head of Research Governance
Research & Impact Services
University House

University of Warwick
Coventry
CV4 8UW
Iimayl: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Miyaa sir lagu hayn doonaa ka qaybqaadashadayda?

Xogta aanan magac lahayn waxaa si adag loo kaydin doonaa muddo 10 sano ah, taasoo ku toosan siyaasadda jaamacadda University of Warwick uga taalla seerferrada jaamacadda ee amni leh iyadoo lagu hayn doono fayl kumbiyuutar oo erey isgarad lagu xiray. Waxaa waqtigaas xogta lagu burburin doonaa hab ku toosan nidaamyada Jaamacadda. Waxaa arki kara oo keliya kooxda cilmibaarista.

Maxaa lagu samayn doonaa natiijooyinka daraasadda ka soo baxa?

Natiijooyinka cilmibaarista ka soo baxa waxaa lala wadaagi doonaa dugsiyada iyo hay'adaha samafalka ah ee ka qayb qaata. Dugsiyada iyo hay'adaha samafalka ah waxaa weliba lagu dhiirrigelin doonaa in ay macluumaadkan u gudbiyaan waalidiinta. Waxaa laga yaabaa in weliba natiijooyinka si aanan magac lahayn looga isticmaalo shirarka iyo daabacaadyada waxbarashada si cilmibaareyaasha looga caawiyo in ay fahan dheeraad ah ka helaan qoysaska kooxdan ku jira.

Yaa daraasadda dib u eegay?

Waxaa daraasaddan dib u eegay oo ra'yi wanaagsan ka bixiyey Guddiga Anshaxa Cilmibaarista Adabka aadamaha iyo Cilmiga Bulshada (Humanities and Social Science Research Ethics Committee) (HSSREC) ee jaamacadda University of Warwick: 70/16-17

Maxaa dhacaya haddii aan rabo in aan macluumaad dheeraad ah ka helo daraasadda?

Haddii aad su'aalo ka qabto dhinac kastoo daraasadda ka mid ah, ama ka qaybqaadashadaada, ee aanan lagaga jawaabin xaashidan macluumaadka ka qaybqaataha, fadlan la xiriir:

Barah Alallawi, jaamacadda University of Warwick, **B.Alallawi@warwick.ac.uk**
Nura Aabe, Ururka Madaxbannaanida cudurka Dhakaakaha (Autism Independence Organisation), **nuraaabe@autism-independence.org**

Waad ku mahadsan tahay waqtiga aad u qaadatay si aad u akhrisato Xaashidan Macluumaadka Ka qaybqaataha.

Appendix O: Consent form (Somali version)- Support needs of Arab families of children with ASD living in the UK

Daraasadda ku saabsan Baahiyaha Taageerada Qoysaska Carabta ah ee Carruurta qabta Cudurka ka mid ah Cudurrada Dhakaakaha ee Ingiriiska ku Nool

FOOMKA OGGOLAANSHAHA

Fadlan taxaddar ku akhriso bayaannada ugu horreeya ee hoose. Haddii aad bayaannadan waafaqsan tahay, haddaba sax ku calaamadee sanduuqa ku habboon. **Waxaa nasiib darro ah, in aanan annagu isticmaali karin jawaabaha aad sahaminta ka bixiso haddii aad oggolaan weydo bayaannada dhammaantood.**

Waxaan xaqiijinayaa in aan anigu akhriyey oo aan fahmay xaashida macluumaadka ee laga bixiyey daraasadda kor ku xusan. Waxaan fursad u helay in aan macluumaadka ka fiirsado, su'aalo jeediyo waxaana kuwan la iiga jawaabay si loogu qanco. ☐

Waxaan anigu fahansan ahay in aan ikhiyaar u leeyahay ka qaybqaadashada. ☐

Waxaan anigu fahansan ahay ka dib marka ay kooxda cilmbaaristu sahaminta helaan, in aanan xogtayda dib ugala bixi karin daraasadda cilmibaarista maadaama ay sahamintu tahay mid aanan magac lahayn. ☐

Waxaan anigu fahansan ahay in xogtayda si adag loo kaydin doono muddo 10 sano ah, taasoo ku toosan Siyaasadda Maamulka Xogta Cilmibaarista ee jaamacadda University of Warwick. ☐

Waxaan anigu oggolaahay in aan ka qayb qaato daraasadda kor ku xusan. ☐

Appendix P: Interview protocol- Special educators' experiences of a numeracy curriculum for pupils with autism spectrum disorder

Interview protocol

Researchable question: What are the views, perceptions and experiences of Calthorpe Academy staff delivering TEN-ID curriculum to pupils with ASD?

Introduction

We are interested in your experience of using the TEN-ID curriculum in your day to day work at the school over the school year 2017/18. We would like to find out what you thought about the TEN-ID curriculum - what went well and what could be improved if you were to use TEN-ID curriculum again.

I would like to thank you for agreeing to talk to us. You have signed a consent form agreeing to take part in the interview. I'll record this interview if you have consented for this, so I can transcribe it later. If you did not consent to audio recording, I will take detailed notes during our conversation. Everything that you tell me today will remain confidential and anonymous. If at any point during the interview you decide you do not want to continue, please let me know. You do not have to give me a reason for your decision.

Our discussion today should last about 30 minutes, but you can talk for as little or as long as you would like. If you are happy with all these, we can begin.

Topic 1: Implementation

1. What is your role in the school and in the TEN-ID project?
2. Tell me about your experience of implementing the TEN-ID curriculum with your pupils?
    - Did you encounter any difficulties?
    - What did you enjoy and what would you change?
3. Could you give me an example of something you found easy and something you found hard in implementing the TEN-ID curriculum?
    - Why?

Topic 2: Training and materials

1. Tell me about your experience of the training that you have received at the beginning of the school on the TEN-ID curriculum?
    - What was useful? (Why? Examples?)

  - What wasn’t useful? (Why? Examples?)
  - What, if anything, would you change?
  - Do you think you need more training?
2. Tell me about your experience of using the TEN-ID materials, including the folder and teaching materials?
   - Was the folder useful? What would you change?
   - Were the materials useful?

Topic 3: Support

1. Tell me about your experience of the mentoring visits?
   - What was useful? (Why? Examples?)
   - What wasn’t useful? (Why? Examples?)
   - Feedback from the trainers (myself and Magda) was part of the mentoring visits, what are your views on it? Did you find it useful?
2. Thinking about the wider school (SLT, heads of departments and your colleagues), how much support have you received?
   - Can you give me some examples?
   - Would you like to have more support?

Topic 4: Outcomes

1. How do you think your pupils are doing after eight months of the TEN-ID curriculum?
   - Why?
   - Examples?
   - Did you notice generalisation of the skills they have learned?
2. Think of a specific pupil that you work with, take me through his/hers journey during this school year.
   - Do you think he/she enjoyed the intervention?
   - Why?
   - How do you know?
3. Thinking about your professional development, did you experience any benefits from learning about and implementing the TEN-ID curriculum?
   - Why?
   - Examples?

4. Thinking about this school year, did TEN-ID have impact on teaching in general in your class?
    - Did it impact pupils that were not working on TEN-ID?
    - Any implication of the knowledge and practice on the TEN-ID on how you work with other pupils?
    - Did the project cause any disruptions to your class?
5. Did the training and experience on the TEN-ID you have acquired during this school year had impact on your confidence in teaching in general?
    - If yes, can you give me a few examples?

Topic 5: Wider implications

1. Can you tell me about your experience of participating in a research project?
    - Did you enjoy it?
    - Did you feel part of the project?
    - Would you like to take part in a research project in the future?
    - Would you like your school to take part in more research projects in the future?
2. Would you like to see the TEN-ID curriculum continue to be used with your pupils?
    - If yes, why?
    - If no, what would have to change?
3. Would you like to see the TEN-ID curriculum being used in the rest of the school?
    - If yes, why?
    - If no, what would have to change?
4. What changes would be helpful to implement the TEN-ID curriculum with pupils with different needs than autism?
    - How about older or younger pupils?
    - Why?

Thank you very much for your time. Are you happy for us to use data from your interview?

Appendix Q: Ethics approval- Special educators' experiences of a numeracy curriculum for pupils with autism spectrum disorder

Friday, 20 April 2018

Professor R Hastings

CEDAR
University of Warwick Coventry
CV4 7AL

Dear Professor Hastings,

Ethical Application Reference: 119/16-17
Amendment number: 1
Title: Evaluation of small group numeracy curriculum for children diagnosed with Autism Spectrum Disorder

Thank you for submitting your project amendments to the Humanities and Social Sciences Research Ethics Sub- Committee for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full approval for your project is hereby granted.

Before conducting your research it is strongly recommended that you complete the on-line ethics course:

https://www2.warwick.ac.uk/services/ldc/researchers/opportunities/development_support/research_integrity/

Support is available from your Departmental contact in Research & Impact Services.

Any material changes to any aspect of the project will require further consideration by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

F MacCallum

Dr Fiona MacCallum
Chair, Humanities and Social Sciences Research Ethics Sub-Committee

Appendix R: Participants information sheet- Special educators' experiences of a numeracy curriculum for pupils with autism spectrum disorder

WARWICK
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PARTICIPANT INFORMATION SHEET

Study Title: Staff members' experiences of a numeracy curriculum for pupils with Autism Spectrum Disorder

Investigator(s): Barah Alallawi and Magdalena Apanasionok (University of Warwick)

Introduction

You are invited to take part in a research study. Your participation in this study will help to understand your views about TEN-ID (Teaching Early Numeracy to children with Intellectual Disability) and your experiences of using the curriculum with children with autism this school year. We are very keen to hear from you. Before you decide, please take time to read the following information carefully. It is important for you to understand what the research would involve. If there is anything that is unclear, or if you would like more information please contact us using the details provided at the end.

Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

During school year 2017/18, some pupils from Autism Department in Calthorpe Academy have been taught numeracy using the TEN-ID curriculum (Teaching Early Numeracy to children with Intellectual Disability). We have assessed pupils' numeracy skills to see if they have made progress while accessing the curriculum. We would also like to understand staff views about TEN-ID and their experiences of using the curriculum with children with autism. This information will help us understand how to better support staff members and pupils and how to improve the curriculum in the future. We would like to interview staff who have used the TEN-ID curriculum during 2017/18.

Do I have to take part?

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time without any repercussions.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Transcribed data will be anonymised, so you will not be identified. Further details are included in Part 2.

What will happen to me if I take part?

You will be invited to attend an interview by Barah Alallawi and Magdalena Apanasionok. The interview will take place at Calthorpe School at a time that suits you. We will explain what is involved and check that you have fully understood everything covered in this information sheet. We also need to check that you agree to participate in the research. Once you have read this study information, you will be asked to read some statements and to indicate your agreement to each one. We will ask if it is ok to audio record an interview with you. You do not have to agree to this recording. You can still take part in the research interview even if you do not want to be recorded. The interview will last about 30 minutes. We shall be asking you about your experiences of delivering TEN-ID curriculum over the school year 2017/18. We would like to find out about your thoughts on the curriculum, particularly what went well and what could be improved if you were to use the curriculum again.

If you say we can record the interview, the research team will transcribe the interview later and destroy the recording. If you do not agree to the interview being recorded, the interviewer will take written notes when they meet with you.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

We do not anticipate any disadvantages or risks associated with taking part in this research. We just want to know about your experiences of delivering the TEN-ID curriculum.

What are the possible benefits of taking part in this study?

Participants in this research study will have an opportunity to discuss/share their experiences of using TEN-ID. We want to understand what we can do to improve TEN-ID in the future.

Expenses and payments

We will not be offering payments for taking part in this study. Taking part in this study will incur no expenses for you.

What will happen when the study ends?

At the end of the study, all interview transcripts/notes and consent forms will be stored anonymously by University of Warwick for 10 years (in line with University of Warwick policy) on secure university servers in a password protected files which only the research team will have access to. The findings may also be used anonymously in academic conferences and publications.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

The University of Warwick is responsible for this research. The research has received funding from:

1. Mutah University (Jordan) who are supporting Barah's Alallawi PhD studies at the University of Warwick.
2. Calthorpe Academy and University of Warwick who are supporting Magdalena's Apanasionok PhD studies at the University of Warwick.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate. You can withdraw at any time without any repercussions. You can also refuse to answer any question that you're not comfortable with.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Will my taking part be kept confidential?

Yes, your name will not be used in any report of the research study and the interview transcripts and notes will be anonymised.

What will happen to the results of the study?

Data from this research will be anonymised and the research findings shared with Calthorpe Academy and the teaching staff. The anonymised findings may also be used in academic conferences and publications.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC): 119/16-17.

What if I want more information about the study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

Barah Alallawi, University of Warwick, B.Alallawi@warwick.ac.uk
Magdalena Apanasionok, University of Warwick, M.Apanasionok@warwick.ac.uk

Thank you for taking the time to read this Participant Information Sheet.

Appendix S: Consent form- Special educators' experiences of a numeracy curriculum for pupils with autism spectrum disorder

WARWICK
THE UNIVERSITY OF WARWICK

CONSENT FORM

Title of Project: Staff members' experiences of a numeracy curriculum for pupils with Autism Spectrum Disorder
Name of researcher(s): Barah Alallawi and Magdalena Apanasionok - CEDAR, University of Warwick
Name of Academic Supervisors: Professor Richard Hastings - CEDAR, University of Warwick

Dr. Corinna Grindle - Associate Fellow, CEDAR, University of Warwick

Dr. Louise Denne - Senior Research Fellow, CEDAR, University of Warwick

Dr. Richard Watkins - Associate Fellow, CEDAR, University of Warwick

Please tick initial box

1. I confirm that I have read and understood the information sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary, and I can withdraw at any time without any repercussions. I can refuse to answer any question that I'm not comfortable with. ☐
3. I am happy for my interview to be audio recorded so the research team can transcribe the interview later. ☐
4. I understand that verbatim quotes from my interview might be used by the research team for research purposes. All used quotes will be anonymized. ☐
5. I understand that my data will be securely stored for 10 years, in line with the University of Warwick's Research Data Management Policy and data from my interview will be transcribed anonymously so I will not be identified. ☐
6. I agree to take part in the above study. ☐

____________________ __________ _______________
Name of Participant Date Signature

____________________ __________ _______________
Name of Researcher Date Signature

Appendix T: Ethics approval- Parent mediated numeracy intervention for children with autism spectrum disorder in Arab families living in the UK

Tuesday, 06 November 2018

Mrs Barah Alallawi

CEDAR
University of Warwick Coventry
CV4 7AL

Dear Mrs Alallawi,

Ethical Application Reference: 09/18-19
Title: Evaluation of a numeracy curriculum implemented by Arab parents with their children diagnosed with Autism Spectrum Disorder

Thank you for submitting your updated ethics application to the Humanities and Social Sciences Research Ethics Sub-Committee, following the letter of conditional approval on **19 October 2018**. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full approval for your project is hereby granted for the duration of the study.

Before conducting your research it is strongly recommended that you complete the on-line ethics course: www.warwick.ac.uk/ritraining. Support is available from your Departmental contact in Research & Impact Services

Any material changes to any aspect of the project will require further consideration by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

Dr Fiona MacCallum
Chair, Humanities and Social Sciences Research Ethics Sub-Committee

Appendix U: Participants information sheet- Parent mediated numeracy intervention for children with autism spectrum disorder in Arab families living in the UK

PARTICIPANT INFORMATION SHEET

Study Title:	Evaluation of a numeracy curriculum implemented by Arab parents with their children who have Autism Spectrum Disorder
Investigator(s):	Barah Alallawi, Professor Richard Hastings and Dr Corinna Grindle (University of Warwick**)**

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. If there is anything that is unclear, or if you would like more information please contact us using the details provided at the end.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

This study will involve testing a new numeracy (maths) curriculum that Arab parents can deliver to their child with autism spectrum disorder (ASD) to improve the child’s numeracy skills. The numeracy intervention is known as TEN-ID (Teaching Early Numeracy to children with Intellectual Disability) and teaches children very early numeracy skills, including: counting objects, recognising numbers and being able to count forwards and backwards. Parents will receive training in how to deliver TEN-ID with their child with autism at home. Each parent will also receive some telephone support from Barah Alallawi to support them in using the TEN-ID intervention with their child with autism. Telephone support will be offered once per fortnight during the 8 weeks project and the support sessions will be approximately 20- 30 minutes each.

We are asking that parents spend approximately one hour (over several short teaching sessions) per week for 8 weeks teaching their child using TEN-ID.

We want to collect some research data to see whether the TEN-ID intervention helps children with autism from Arab families living in the UK with their maths skills. We will do this in two ways. First, a researcher will meet your child in your home when you are there too. The researcher will test your child's maths skills. The researcher will carry out this test before the TEN-ID intervention starts and also at the end of the 8 weeks of the study. The test is not a time limited and can last from 10 to 60 minutes depending on child's skills. Second, at the end of the 8-weeks period, we will invite all parents to take part in an interview to ask you what you thought about the TEN-ID intervention used with your child with autism. In particular, we will ask you about the things that went well with TEN-ID and any things that did not go so well.

Parents who originate from one of the following 22 Arab league states and who are currently living in the UK can take part in the research (Algeria, Somalia, Egypt, Libya, Sudan, Tunisia, Morocco, Mauritania, Djibouti, Bahrain, United Arab Emirates, Oman, Kuwait, Qatar, Saudi Arabia, Yemen, Jordan, Syria, Iraq, State of Palestine, Lebanon, and Comoros). You need to have a child who has been diagnosed with autism (you just need to tell us that your child has been diagnosed with autism; we do not need to see confirmation of this) and who is between 4 years and 15 years old. Also, your autistic child should have some verbal abilities using single words either in English or Arabic, have the necessary prerequisite skills to be able to benefit from the programme (e.g., sitting willingly at a table to engage in learning tasks for short periods of time (up to 15 minutes) and be able to follow simple one step instructions (e.g., 'clap hands'). Your child should have few counting skills (e.g., can name some but not all numerals in the range 1-10). TEN-ID is available in English or Arabic depending on parents' preferences. Teaching resources will also be provided to use at home with your child with autism.

Do I have to take part?

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time without any repercussions. If your child refuses to take part in the test of their maths skill, or they seem unwilling to be tested, this is also no problem and the researcher will not do the maths test.

What will happen to me if I take part?

Once you have read this study information, you will be asked to read some statements and to indicate your agreement to each one. We need to check that you agree to participate in the research. Your child's numeracy skills will be assessed using the Test of Early Mathematics Ability – Third Edition (TEMA 3). This is a standardised assessment that has been used with many children with special educational needs, with no problems and no distress for the children.

You will be then trained on the TEN-ID numeracy programme by the researchers so that you can implement it with your child at home. TEN-ID will be provided in English or Arabic depending on your preferences. All teaching materials will also be provided to use at home. We will offer support, troubleshoot with you if needed, and provide feedback.

We are also very keen to hear from you about your views on implementing TEN-ID with your child over the 8 weeks period. Thus, at the end of the intervention, we would like to conduct an interview with you. The interview will take place at a time that suits you. We will ask if it is ok to audio record the interview with you. You do not have to agree to this recording. You can still take part in the interview even if you do not want to be recorded. The interview will last about 30 minutes, and ideally we would carry out the interview over the telephone.

If you say we can record the interview, the research team will transcribe the interview later and destroy the recording. If you do not agree to the interview being recorded, the interviewer will take written notes when they talk with you. You also are free to stop doing the TEN-ID sessions at home at any time if you wish to and you do not have to give a reason why. If you do decide to stop doing the TEN-ID sessions at home this will not affect your child in relation to what she/he receives at school. However, if you do decide to stop doing the TEN-ID sessions at home we will still ask you if you would be willing to be interviewed 8 weeks after the beginning of the intervention to talk to you about your opinion of the teaching package, the training of the teaching package and how you found teaching your child at home.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

We do not anticipate any disadvantages or risks associated with taking part in this research.

What are the possible benefits of taking part in this study?

Parents participating in this research will learn how to teach numeracy skills to their child with autism and so the children will have an opportunity to develop their numeracy skills.

Expenses and payments

We will not be offering payments for taking part in this study. Taking part in this study will incur no expenses for you except for travel to a location near to your home to receive the initial TEN-ID training from the research team.

What will happen when the study ends?

At the end of the study, the maths test data from your child and transcripts of the interview with you will be stored anonymously by University of Warwick for 10 years (in line with University of Warwick policy) on secure university servers in a password protected files which only the research team will have access to. The findings may also be used anonymously in academic conferences and publications.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

The University of Warwick is responsible for this research. The research has received funding from Mutah University (Jordan) who are supporting Barah Alallawi's PhD studies at the University of Warwick.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect any other services that you receive. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate. You can withdraw at any time without any repercussions.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:
Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Will my taking part be kept confidential?

Yes, your name and your child's name will not be used in any report of the research study and data from TEMA 3 assessments and the interview transcripts will be anonymised.

What will happen to the results of the study?

Data from this research will be anonymised and the research findings shared with you. The anonymised findings may also be used in academic conferences and publications.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC): 09/18-19.

What if I want more information about the study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

Barah Alallawi, University of Warwick- **B.Alallawi@warwick.ac.uk**
or telephone **07459824593**

Thank you for taking the time to read this Participant Information Sheet.

Appendix V: Consent forms- Parent mediated numeracy intervention for children with autism spectrum disorder in Arab families living in the UK

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THE UNIVERSITY OF WARWICK

CONSENT FORM

Title of Project: Evaluation of a numeracy curriculum (TEN-ID) implemented by Arab parents with their children who have Autism Spectrum Disorder.

Name of researcher: Barah Alallawi- CEDAR, University of Warwick

Name of Academic Supervisors: Professor Richard Hastings - CEDAR, University of Warwick and Dr. Corinna Grindle - Associate Research Fellow- CEDAR, University of Warwick

Please initial box

1. I confirm that I have read and understood the information sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary, and I can withdraw at any time during the research study without any repercussions. ☐
3. I am happy for my child to take part in a maths test before and after they have received TEN-ID, if my child is willing to do so and under my supervision. ☐
4. I understand that I can refuse to let my child take part in the maths test either before or after we have used TEN-ID. ☐
5. I understand that at the end of the research study, I will be invited to take part in an interview with Mrs. Barah Alallawi. I am happy to take ☐

part in an interview over the telephone. I understand that I can refuse to take part in the interview.

6. I am happy for my interview to be audio recorded so the research team can transcribe the interview later. I understand that I can change my mind about this at any time. ☐

7. I understand that verbatim quotes from my interview might be used by the research team for research purposes. All used quotes will be anonymized. ☐

8. I understand that my data will be securely stored for 10 years, in line with the University of Warwick's Research Data Management Policy. ☐

9. I agree to take part in the above study. ☐

Name of Parent	Date	Signature
Name of Researcher	Date	Signature

Appendix W: Teaching plan for the first target of the emergent stage (Arabic version)

الهدف أ1.1 ●	يقول الطفل الأعداد من 1 الى 20 بالتسلسل.
قول الاعداد تصاعدياً بالتسلسل	
الأدوات التعليمية المستخدمة	لاشيء
اسلوب التدريس	تأكد أن الطفل مستعد للدرس بحيث ينظر الى الأدوات التعليمية المُستخدمة وينظر اليك. **قول الاعداد تصاعدياً بالتسلسل وذلك باستخدام نموذج التلقين (يقوم الأب/الأم بتقليد المهارة– قول الأعداد – أمام الطفل)** الأب/الأم: قُل للطفل "هيّا نُعد.1،2،3". ثم قُل للطفل "الاَن دورك" الطفل: يكرر "1،2،3". قُم بتعزيز اجابة الطفل. **عندما يتقن الطفل ذلك**، استمر باستخدام نفس الأسلوب مع الأعداد التالية: 4-7، 6-10، 1-5، 6-10. **قول الاعداد تصاعدياً بالتسلسل بدون استخدام نموذج التلقين (لايقوم الأب/الأم بتقليد المهارة امام الطفل)** الأب/الأم: قُل للطفل "عد من 1 الى 5". الطفل: يقول "1،2،3،4،5 ". عندما يتقن الطفل ذلك، استمر باستخدام نفس الأسلوب مع الأعداد التالية: 6-10، 1-10، 7-10، 11-15، 15-20. يجب على الطفل أن يُجيب خلال 3 ثوان من تلقيه السؤال/التعليمات من قبل الأب/الأم وذلك من خلال قول الأعداد تسلسلياً بشكل صحيح. اذا لم يتم ذلك، يرجى الرجوع الى قسم: المساعدة التي يمكن تقديمها. اختبر كل مهارة جديدة لترى اذا كان الطفل قادر على تعميم الفكرة. اذا كانت اجابة الطفل صحيحة على المهارة الجديدة من المحاولة الاولى لست بحاجة الى تدريسها ويمكنك الانتقال الى المهارة التالة. تذّكر أن تُسجّل ذلك في ملف الطفل
خطة التعميم	- شخص اخر من الاسرة يسأل الطفل القيام بالمهارة، مثلاً الأب،الجدة، الجد، أخ الطفل أو أخته.

	– استخدام تعليمات مختلفة، على سبيل المثال، قل للطفل "قلدني: 3،2،1". – تدريب الطفل على المهارة في أماكن مختلفة (مثلاً في غرفة الطفل، غرفة الجلوس أو في المطبخ) أو خلال أوقات مختلفة خلال اليوم (مثلاً وقت الاستحمام أو وقت العشاء).
المساعدة التي يمكن تقديمها	– تقليد المهارة: يقوم الأب/الأم بتأدية المهارة امام الطفل اولاً ومن ثم يقوم الطفل بتقليده. يجب التقليل تدريجياً من تقليد المهارة امام الطفل. – اذا قام الطفل بحذف عدد (مثلا، يقول 5،3،2،1). في المرة القادمة قم بالعد امامه وقل العدد الذي يحذفه بصوت عالي جداً (3،2،1، **4** بصوت عالي جداً،5). – اذا لم يتقن الطفل المهارة (العد من 1–5)، قم بتدريسه أولا 5،4 حتى يتم الاتقان ومن ثم انتقل الى تدريسه 5،4،3، وبعدها 5،4،3،2 – اذا استمر الطفل بالعد بعد العدد المطلوب منه مثلا يقول 6،5،4،3،2،1... ارفع يدك امام الطفل كاشارة له بان يتوقف عن العد عند العدد المطلوب منه أو يمكنك عرض بطاقة عليها العدد 5 حتى اذا لم يكن الطفل قد تعلم حتى الان ان يميز العدد. – كل مهارة يمكن عرضها على الطفل مبدئياً من خلال مجموعة قصيرة من الاعداد المتسلسلة مكونة من عديدين ومن ثم الانتقال تدريجيا الى عرض مجموعة طويلة من الاعداد المتسلسة مكونة من 5 أعداد.
معيار اتقان المهارة	3 محاولات صحيحة خلال 3 أيام متتالية.

Appendix X: Teaching plan for the target 'saying short forward number word sequences from 1 to 20

Target: A1.1	The child says short number word sequences from 1 to 20
Saying Short Forward Number Word Sequences (FNWS)	
Materials	None
Teaching Procedure	Check that the child is ready to learn (looking at the teaching materials, looking at the parent, etc). **For saying FNWSs with a modelling prompt.** Parent: 'Let's count. 1, 2, 3. Now your turn' Child: Repeats: '1, 2, 3'. Reinforce the response. **Once mastered**, continue the procedure with 4 to 6, 7 to 10, 1 to 5 and 6 to 10. **For saying FNWSs without a modelling prompt**. Parent: 'Count from 1 to 5'. Child: Says '1-2-3-4-5'. **Once mastered**, continue the procedure with 6 to 10, 1 to 10, 7 to 10, 11 to 15, and 15 to 20. The child should respond within 3 seconds after the instruction has been given and say the correct number sequence. If not, please refer to: Help that may be provided. Test each new task see if the child generalises the idea. If the child is correct on the first attempt on a new task, you do not need to teach this task, and you can move on to the next task. Remember to register this in the folder. Thus, probe (test) random FWNSs in range 1-10 without a modelling prompt (e.g., 'Count from 4 to 7' and child says '4, 5, 6, 7'). Then random next FWNSs in range 11-20 without a modelling prompt (e.g., 'Count from 11 to 15' and child says '11, 12, 13, 14, 15').

	If the child struggles with these extensions to the task they will need to be systematically taught using the procedure outlined previously.
Generalisation plan	• Another person in the family – e.g. child's dad, sibling or grandparent asks the child to count. • Use different instructions – e.g. 'copy me: 1-2-3' or sing songs that involve forward number word sequences – e.g. '1-2-3-4-5, once I caught a fish alive, 6-7-8-9-10 then I let it go again". • Practice in different places – e.g. (in the kitchen, in the dining room or in the park) or at a different time of the day- e.g. (at bath time or at lunch time).
Help that may be provided	• Model - the parent demonstrates first and the child copies after. This should be faded over subsequent trials. • If the child omits a number (e.g. says 1, 2, 3, 5), the next time the sequence is modelled say the omitted number in a very loud voice, e.g. 1, 2, 3, 4 (loud), 5. • If the error continues, count backward and/or forward for example, work on 4, 5 until consistent, then on 3, 4, 5, then on 2, 3, 4, 5 etc. • If the child continues counting on (e.g. says 1, 2, 3, 4, 5, 6…) put up your hand to indicate when the child should stop. Or show a number card instead (e.g., card with the number 5), even if the child has not yet learned to recognize the number. • Each step can be introduced initially with shorter number word sequences (e.g., with 2 numbers), gradually building up to the longer sequences (e.g., 5 numbers).
Mastering criterion	Three ticks (√) in a row across 3 consecutive days.