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Meeting the needs of pupils with autism in Qatar

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Meeting the Needs of Pupils with Autism in Qatar: Moving forward

wise
world innovation summit for education
مؤتمر القمة العالمي للابتكار في التعليم
An Initiative of Qatar Foundation

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UNIVERSITY OF BIRMINGHAM | ACER AUTISM CENTRE FOR EDUCATION AND RESEARCH

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RR.8.2017

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Elaine Ashbee
Lila Kossyvaki
Ryan Bradley
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Foreword

Improving awareness and understanding of disability and conditions such as autism has long been a difficult global challenge. Misconceptions and limited awareness about autism persist. Even in wealthier societies people with autism — PWA — lack adequate, appropriate support, and struggle to hold jobs and find ways to thrive. The quality of integration among education, health and social service sectors varies greatly. In Qatar, which has experienced dramatic economic growth over just twenty years, attention to special needs in education is relatively recent. But thanks to the sensitive and committed interest of Qatar's leadership, progress is being made. With the Qatar National Autism Plan in place, the country is poised to make a significant contribution toward building an effective, cohesive, and culturally authentic approach to the lifelong care and education of people with autism.

This WISE Report, produced by our colleagues at University of Birmingham and the Autism Centre for Education and Research, presents a full and frank portrait of the needs of PWA in Qatar. The report calls for targeted awareness campaigns designed to portray autism not as illness or deficiency, but as 'difference'. It emphasizes the need to involve PWA themselves in developing policies and practices that directly impact them. Among its compelling strengths are the poignant interviews and focus group studies, revealing the range of challenges diverse stakeholders face, from individuals, parents and families, to religious leaders, health professionals, researchers, education leaders and policy makers. The report sensitively considers perceptions of autism, child development, and the role of schools in Arab gulf society. Its exploration of issues mainstream schools face in managing students with special needs, such as the various perspectives on what 'inclusion' means in practice, and the struggle to integrate the work of Arabic and English-speaking staff are all valuable contributions.

The report appears at a crucial point of conversion in Qatar's development from a 'knowledge economy' to a 'knowledge society'. The campaign it explores to develop sophisticated, human-focused systems for the health and education of PWA suggests the transitions Qatar is undergoing as a whole. Where once priorities in examining issues of disability and autism were in biology, risks and diagnostics, now the focus has shifted toward services and provision, treatment and intervention. In Qatar today, the real work ahead in many sectors is in developing integrated human systems of expertise, practice, and public outreach. Qatar is perhaps poised to blaze a way ahead as a unique model for managing the care and education of PWA in the Arab Gulf through the cohesive and integrated processes this report advocates.

Qatar has already demonstrated its serious commitment to special needs education as outlined in this report and in stated national priorities. The Renad Academy and the Teaching and Learning Center, both at Qatar Foundation, as well as Al-Hidaya kindergarten, the Shaffallah Center and other facilities represent a solid beginning. Progress is steady. The process of finding what works will likely present further hurdles as families and communities struggle to understand and manage the needs of PWA among them. Yet many already grasp that people with autism can have dreams too, and that these can be met and can inspire others. They, their families, community leaders, educators and specialists, will continue to press for progress and improvement so that the systems themselves come to reflect the best aspirations of those they serve.

Stavros N. Yiannouka
CEO
WISE

Executive Summary

The Qatar National Autism Plan (NAP) 2017-2021[1] was launched in April 2017. This addresses the needs and rights of autistic people and their families, and focuses on the six pillars of awareness; early recognition and screening; diagnosis and assessment; interventions; education and transition into adolescence, adulthood and elderhood. A number of stakeholders and ministries are involved in implementing this plan and it highlights the commitment of the Ruling Family, the government and stakeholders to driving forward change in this area.

This research was commissioned by the World Innovation Summit for Education (WISE), an initiative of the Qatar Foundation, to address how to strengthen the education pillar of the Qatar National Autism Plan 2017-2021, given the importance of the role of education in social inclusion and quality of life for autistic people and their families.

Aims & Methodology

The study examines how far Qatar has come in implementing its vision of educational inclusion, identifies the barriers to realizing this vision, and makes recommendations for how to improve autism education.

The research consists of:

1. A contextual enquiry investigating conceptions of inclusive educational practice and provision in Qatar, drawing on international and national literature and policies.

2. Empirical research that gathered stakeholder perspectives to understand the views, perspectives and experiences of those who engage directly in policy, practice and provision. Focus groups (n=14) and semi-structured interviews (n=9) captured the perspectives of 71 participants who care for, work with, or are engaged in developing policy for individuals with autism.

Three overarching themes emerged:

- Awareness, Knowledge and Understanding
- Policy, Provision and Practice
- Personal and Professional Development

1. Although the NAP was launched in April 2017, it had not yet been published at the time of us conducting this research. We were therefore unable to reference the NAP beyond alluding to the six pillars.

Findings

Awareness of autism has clearly increased in Qatar, and there have been a number of excellent initiatives. Misconceptions about autism nevertheless still exist, and there is a need to continue raising awareness of autism. Despite the existence of pockets of excellent practice, there is still patchy diagnostic and post-diagnostic support and many parents feel lost post-diagnosis. In moving forward, the priority will be to ensure that autistic people and their families have full access to excellent and mandated diagnostic, post-diagnostic and early intervention services.

In education, there is need to collate further data on the numbers of pupils with autism and to develop an appropriate range of provision for all children and young people with autism, whether they are Qatari or expatriate. Educators need to know more about which approaches, interventions and services are most appropriate for children and young people in Qatar. Teachers and schools also need more tools and good professional development to help them provide a differentiated curriculum and pedagogy that takes account of the specific needs to pupils with autism.

Social and leisure facilities need to be extended for autistic people. Provision is needed for vocational training, housing, further education and college opportunities for autistic young people and adults, and for supporting transitions between stages of schooling and from school to adult services.

Personal and professional development is currently disjointed, and there are concerns about the quality of training. In addition, most materials and resources to diagnose, assess, and teach are developed in English speaking countries and there is a need for homegrown, local and culturally appropriate materials. There is a need for larger numbers of specialist staff with knowledge of Additional Educational Special Needs (AESN) or autism. Current levels of knowledge among parent organizations and staff in specialist provisions could be harnessed to enhance the knowledge, understanding and skills of a greater number of therapeutic and educational staff.

Key Recommendations

Awareness, knowledge & understanding

- Develop and implement culturally appropriate diagnostic and assessment instruments, as well as training programs for health and therapeutic staff so that the number of professionals offering diagnostic services and post-diagnostic support is increased.
- Promote awareness campaigns that focus on autism as a different, rather than deficient or disordered way of being. Ensure that these cascade knowledge about child development, and about red flags in particular. Engage key religious leaders in challenging conceptualizations of autism as an illness, and in leveraging Islamic teachings in raising awareness of autism.
- Conduct further research to gather the views and experiences of children and young people with autism so that their perspectives can inform professional and personal development programs in autism education.

Policy, provision & practice

- Mandate post-diagnostic support and early intervention provision.
- Undertake further work to determine numbers of autistic children and young people in order to inform educational planning and ensure that an appropriate range of provision is developed.
- Investigate which approaches and interventions are most appropriate for autistic pupils and their families in Qatar so that approaches and interventions are underpinned by research as well as the individual needs of the pupil and their family.
- Develop a strategy and implementation plan for supporting the transition of autistic people into adulthood and for providing a range of opportunities and services in adulthood. Identify a range of centers, and social and sports activities that will accommodate the needs of individuals with autism. Schools and other professionals should make extensive efforts to ensure that autistic students are consulted in decisions that ultimately affect their lives, especially at key transition points.

Personal & professional development

- Develop a website that provides information about autism, and the evidence base for approaches and services, as well as a range of practical resources and relevant material to support parents, educators and individuals with autism.
- Gather highly qualified bilingual professionals, parents and individuals with autism to coordinate efforts to develop culturally appropriate diagnostic and assessment instruments along with training materials and information for parents. This could include the development of a progression framework that is relevant to Qatar alongside a set of National Standards for settings and a Competency Framework for practitioners.
- Establish an accreditation system for personal and professional development, with a professional body that oversees it and that draws on the expertise and knowledge that currently exists in Qatar. Current providers should be supported to develop in-depth University-based provision further.
- Set up an interdisciplinary research centre for excellence in autism education that integrates efforts from Gulf countries and the wider Arab world.

Summary & Conclusions

There is great potential to improve awareness, knowledge and understanding of autism alongside the development of policy, practice and provision in Qatar, as there are high levels of knowledge among parent organizations and staff in specialist provisions. This knowledge could be harnessed to enhance the knowledge, understanding and skills of a greater number of therapeutic and educational staff.

In moving forward, the priority will be to ensure that autistic people, their families and caregivers have access to effective support through the diagnostic process and post-diagnosis, and that requisite educational support is available.

We recommend that a cross-ministerial committee is set up to oversee development of provision and policy and that a collaborative network is funded to develop and implement the recommendations related to awareness, knowledge and understanding, as well as personal and professional development. People with autism and their families should have representation on the board, alongside key stakeholders and professionals from a number of organizations.

Acronyms

ABA: Applied Behavioural Analysis
ACER: Autism Centre for Education and Research, University of Birmingham, UK
ADHD: Attention Deficit Hyperactivity Disorder
AES: Additional Educational Support
AESN: Additional Educational Support Needs
AET: Autism Education Trust
ASD: Autism Spectrum Disorder
BREI: British Education Index
CRPD: Convention on the Rights of Persons with Disabilities
EAL: English as an Additional Language
EBP: Evidence Based Practice
EEG: Electroencephalogram
EFA: Education for All
EIBI: Early Intensive Behavioral Intervention
ERIC: Education Resources Information Centre
ESDM: Early Start Denver Model
ICT: Information and Communications Technology
IEP: Individual Education Plan
Mada: Qatar Assistive Technology Center
MMR: Measles, Mumps and Rubella.
MoEHE: Ministry of Education and Higher Education
MRC: Medical Research Council
NAP: The National Autism Plan
NCSE: National Council for Special Education
PE: Physical Education
PECS: Picture Exchange Communication System
QBRI: Qatar Biomedical Research Institute
RTI: Response to Intervention
SCERTS: Social Communication, Emotional Regulation and Transactional Support
SEC: Supreme Education Council
SEN: Special Educational Needs
SEND: Special Educational Needs and Disabilities
SLT: Speech and Language Therapy
SWBP: Students with Behavior Problems
SWD: Students with Disabilities
SWLD: Students with Learning Difficulties
SWLP: Students with Learning Problems
SWSLD: Students with Specific Learning Difficulties
TEACCH: Treatment and Education of Autistic and Communication Handicapped Children
TLC: Teaching and Learning Centre

UAE: United Arab Emirates
UK: United Kingdom
UN: United Nations
UNESCO: United Nations Educational, Scientific and Cultural Organization
US: United States
VAK: Visual, Auditory and Kinesthetic
WAAD: World Autism Awareness (Acceptance) Day
WISE: World Innovation Summit for Education
WISH: World Innovation Summit for Health

Introduction

Why This Research is Needed

Qatar has a history of involvement in international efforts to improve education for children and youth with disabilities (Al-Hendawi et al., 2017). In March 2007, the country signed the United Nations *Convention on the Rights of Persons with Disabilities* (United Nations, 2008). The *Qatar National Development Strategy 2011-2016* included specific steps to be taken in relation to special educational needs so that the country could reach the goal of an educated population, and is outlined in the *Qatar National Vision 2030* (General Secretariat for Development Planning, 2009), as one of its human development outcomes (Al-Hendawi, et al., 2017).

Both governmental and non-governmental organizations have been active in protecting rights, and improving educational opportunities (Hadidi & Al-Khateeb, 2015). This has included being committed to a comprehensive education service that can provide appropriate education to all children and young people. The Additional Educational Special Needs Policy Document, for example, asserts that:

> *Inclusive education is a process of enabling all students to learn and participate effectively within mainstream schooling systems and in mainstream classrooms. Placing previously excluded students within a mainstream setting, however, does not of itself achieve inclusion. Whole school policies and practice need to result in the development of agreed strategies for ensuring that inclusion is achieved in an effective way, enabling all students to access the full range of curriculum opportunities and experiences* (Supreme Education Council, 2009).

Within this broader vision of developing inclusion for pupils with additional educational special needs, there has been a specific focus on improving the lives of people with autism. The Qatar NAP 2017-2021, a plan implemented with the involvement of a number of Ministries, was launched in April 2017,[2] with a focus on the six pillars of awareness: early recognition and screening; diagnosis and assessment; intervention; education and transition into adolescence; adulthood and elderhood. The Ruling Family and government have been central to this process, and the involvement of key stakeholders and parents have been a key driving force. There is commitment at the highest level to moving towards an inclusive society, and to enhancing awareness of autism along with improving educational practice and provision. This goes further than merely being enshrined in law as recent developments include the establishment of the Rou'a Assessment, Advice, and Support Center, the opening of Al-Hidaya, a new kindergarten for Qatari children with autism, and the state of the art Renad Academy, a Qatar Foundation school for children with autism.

2. Although the NAP was launched in April 2017, it had not yet been published at the time of us conducting this research. We were therefore unable to reference the NAP beyond alluding to the six pillars.

Understanding how far Qatar has come in implementing its vision of inclusion, identifying the barriers to realizing it, and making recommendations for how to improve autism education is crucial. This is particularly important in a country such as Qatar where special education provision is relatively young, services are expanding, and efforts are being undertaken to improve quality. This can in turn enable deeper understanding of inclusion across national boundaries (Booth & Ainscow, 1998), provide new perspectives (Corbett, 2001), while also identifying the most effective means of improving educational support and provision in Qatar itself.

Although the literature on special education in Arab countries is growing rapidly, much more needs to be done to establish solid research support for educational practices that are successful in the Arab world (Alnemary et al., 2017). Challenges clearly exist in the Gulf countries with few studies on inclusive and special education, and limited potential for applying the findings into schools and settings (Al-Khateeb, 2010). Although autism research in the Arab world represents a growing field, a recent review found that less than 10 percent of studies focused on treatment and interventions, with most studies focusing on biology, risk factors and diagnosis (Alnemary et al., 2017) or on aetiology (see glossary for explanation of this term) rather than on services and provision (Al-Gain & Al-Abdulwahab, 2002). This highlights the need to study clinical and educational topics in Qatar and to take account of the cultural, political and social context of the country to see how inclusion can be developed further (Clough & Corbett, 2000).

Early intervention and consistent support that is sustained over time and in different contexts is crucial to ensure the right to a broad and relevant curriculum that provides access to the knowledge, skills and social values that are available to all others within society (Guldberg, 2010). International studies have identified a prevalence rate of between 1:100 (Baird et al., 2006) and 1:68 (Centre for Disease Control and Prevention (CDC), 2014) or 1:38 (Kim et al., 2011) in the autism population. The Qatar Biomedical Research Institute (Alshaban et al., 2017) has conducted the main prevalence studies undertaken in Qatar. They have identified prevalence rates of 6 to 7 per 1000 in the low probability group (children in mainstream education). Once they have data for the high probability group they will determine a general prevalence rate for Qatar. If one calculated the prevalence rate by using the most conservative estimate (1:100), there would be approximately 2450 pupils with autism in Qatar, as there are 245,000 pupils in schools currently.

Appropriate provision is needed for these pupils and educational practitioners need to understand how to recognize whether a child might be on the autism spectrum, develop insight into how the child or young person with autism learns and perceives the world differently, and find ways of enhancing teaching and care to address that difference and support inclusive practices (Jordan, 2008). This requires knowledge and understanding of the learning needs, strategies and approaches for pupils with autism. We therefore touch on our use of terminology, the international literature on the specific learning needs of autistic pupils, the evidence base for provision and practice, and key debates on inclusive autism educational practice, before outlining the methodology and findings of our research.

A Note on the Use of Terminology

Terminology is a hotly contested issue in the autism educational sphere. Kenny et al. (2015), for example, elicited the views of UK community members in the field of autism and found that the term 'autistic' was preferred by a large percentage of autistic adults and their families, with the term 'on the autism spectrum' being endorsed by the majority of professionals. Their findings indicated that there is no single universal way of describing autism. In this report, we recognize that the debate about terminology is complex, and even more so when considered in the international context. We respect the different justifications, as well as recognizing that there are language and cultural sensitivities. The authors of this report have decided to use the terms 'with autism' and 'autistic' interchangeably to indicate our acceptance of different perspectives. We are nevertheless consistent about *not* using the term 'disorder' when describing people on the autism spectrum as we see autism as a different rather than deficient or disordered way of being. Throughout this report we refer to 'autistic individuals' or 'individuals on the autism spectrum' to include all those who have a diagnosis of autism or any other autism spectrum condition.

The Specific Learning and Developmental Needs of Autistic Pupils

Autism is a lifelong condition that affects the way that a person communicates and relates to people and the world around them (Daly et al., 2016). It is a spectrum condition, which means that all people with autism share certain features, but their autism affects them in unique, heterogeneous and different ways (Jones & Jordan, 2008). Pupils with autism may learn and develop in different ways than other pupils (Jordan, 2005). There are four key areas of difference that impact how a pupil might learn in an early years setting or school (Guldberg et al., 2011). Firstly, the pupil will have different ways of understanding communication and language, including tone of voice, facial expressions and gestures. Secondly, this will be closely interrelated with differences in understanding social behavior and feelings. Thirdly, interests and information processing will affect how the pupil with autism understands the world and processes information, and can also affect planning, generalizing and predicting as well as transitions and passions or interests. Finally, differences in perceiving sensory information can lead to low or high sensitivity in any of the senses (Daly et al., 2016).

Given the heterogeneous nature of autism, and taking individual abilities and needs into account, pupils with autism will require support in a range of areas. This will include developing the skills, knowledge, and understanding necessary to be able to:

- Communicate effectively in social situations
- Develop and maintain relationships
- Predict and manage change
- Access the curriculum
- Achieve educational outcomes in line with potential
- Adapt and manage the environment to lessen the impact of sensory processing issues
- Regulate behaviors and emotions
- Manage repetitive and restricted patterns of behavior
- Generalize the skills learned in the classroom or home or community

(Bond et al., 2015)

The Evidence Base for Provision and Intervention

There are clearly many strategies, approaches, therapies and interventions for improving the lives of autistic people. 'Research Autism' is a website dedicated to researching the wide range of treatments and interventions in autism. This site currently contains over a thousand interventions in the field of autism along with indications of the evidence base (Milton, 2014). The definitions, criteria, and classifications of these approaches have been categorized in different ways in the literature. One way has been to group approaches according to the number of areas of development they address (NCTL, 2014):

- ***Comprehensive Treatments Models*** focus on many areas of development and can be argued to cover needs in all areas. Examples include Early Intensive Behavior Intervention (EIBI), Treatment and Education of Autistic and Communication Handicapped Children (TEACCH), or Social Communication Emotional Regulation Transactional Support (SCERTS).
- ***Intervention Packages*** cover fewer areas of functioning and behavior. Examples include peer training and social skills packages.
- ***Focused Intervention Packages*** target very specific skills or behaviors in areas of functioning such as play, cognition, or behavior.

In the past decade, a number of systematic international literature reviews have examined the evidence base for different interventions and approaches for pupils with autism (Parsons et al., 2009; Odom et al., 2010; Wong et al., 2015). The main findings from the National Council for Special Education (NCSE) review by Parsons et al. (2009) were that most educational approaches

and programs had some evidence of their effectiveness, but varied in quality, and no approach had been entirely successful in producing a methodologically sound evaluation. Several reviews have found that there is no evidence to suggest that a single intervention will meet the needs of all learners, or that any single intervention or technique stands out from the others as superior for a majority of children (Parsons et al., 2011; Odom et al., 2010; Wong et al., 2015).

The National Autism Centre (2009) in the United States (US), for example, conducted a systematic review of the evidence, and identified eleven 'treatments' for which there is evidence of effective practice (NAC, 2009). Meanwhile the National Professional Development Center found 27 practices that met their criteria of strong evidence (Wong et al., 2015). Another systematic literature review (Bond et al, 2015) found that interventions that were designed to increase joint attention and comprehensive early intervention programs were rated as having most evidence for pre-school children. For school children, peer mediated interventions supporting the development of social skills were the strongest (Bond et al., 2015).

Intervention research in autism is complex as it involves many different strategies while simultaneously measuring a limited range of outcomes (Howlin, 2010). In addition, research studies often have limited sample sizes, focus on relatively short term gains and sometimes struggle with isolating intervention effects from other variables (Horner et al., 2005). A further problem relates to the fact that many studies are efficacy studies that take place in ideal conditions that are carefully controlled (Dingfelder & Mandell, 2011). Difficulties inherent in evaluating approaches for those on the autism spectrum include gaining a clear description of the rationale, aims and practices of an approach; as well as having confidence in the diagnosis and in the assessment results for matching purposes and for measuring change (Horner et al., 2005). Many autistic individuals may be engaged in more than one approach and move in and out of these during the research, and a person may improve for a variety of reasons not related to the approach (e.g. maturation; expectations; family input; other staff input) and their intellectual ability (Guldberg, 2016). In education, there are usually a number of variables that are difficult to pin down and measure, and there is a need to understand what happens naturally (Kasari & Smith, 2013). Furthermore, studies in controlled context might not be relevant to educational contexts (Guldberg et al., 2017).

Given that the education system focuses on the acquisition of academic and functional knowledge and skills through facilitating learning, eligibility for special educational support should be based on an educational determination of need rather than a medical diagnosis (Jones et al., 2008). In classrooms that educate pupils with autism, interventions need to be individualized according to pupil characteristics, include real life outcome measures, and be generalizable to complex real-life conditions and multiple cultures and settings (Mesibov & Shea, 2010). Practitioners, therefore, need to consider the research evidence and draw on interventions that have an evidence base while also taking into account important factors such as the pupils' individual

needs and experience, parental input, professional judgment and assessment, and the experience, capacity and training of teachers and schools (Guldberg, 2016; Bond et al., 2015), thus aiming for a bespoke approach for each pupil and context. The teacher working with a child with autism needs to understand the child and how autism impacts on the child and the family, before deciding which strategies or interventions might work and how these might be implemented in particular contexts (Jordan, 2007).

Rather than advocate for one intervention or approach for *all* autistic individuals, there has been therefore significant effort to produce a number of guidelines to support policy and practice, and to develop basic principles of good autism practice in education and therapy (see Medical Research Council (MRC), 2001; National Institute for Clinical Excellence (NCSE), 2013; New Zealand Guidelines, 2016). The MRC (2001) guidelines, for example, highlight the importance of entry into intervention programs as early as possible. They stress the need for the active engagement of autistic pupils in intensive instruction and for repeated and planned teaching opportunities with sufficient attention daily. These guidelines further highlight that systematically planned and developmentally appropriate activities should target identified objectives, include a family component, and conduct ongoing assessment of progress.

This should be complemented by specialized instructions in settings that permit ongoing interactions with typically developing children (MRC, 2001). In the UK, the NICE (2013) guidelines emphasize the importance of adjustments to the social and physical environment; the information and involvement of autistic people in decision-making; support for families (including siblings); the development of life skills; the need for developmentally appropriate intervention, and for increasing understanding of, and responsiveness to, the child or young person's patterns of communication and interaction by those who care for or work with the autistic individual (NICE, 2013).

Recent reports have highlighted the importance of grounding practices and research in the lived experience of the autistic community (Wittemeyer et al., 2011). Autistic people and their families are rarely involved in making decisions that shape their lives (Milton & Bracher, 2013) and should be key to identifying research priorities (Pellicano, 2014). This also applies to practice in schools. The UN Convention on the Rights of Persons with Disabilities (Article 7.3) states that children with disabilities should be able to express their views freely, on an equal basis with other children, and according to their age and maturity. They should be provided with the appropriate assistance to realize that right. Schools and other professionals therefore need to make extensive efforts to ensure that autistic students have a say over the decisions that ultimately affect their lives, especially at key transition points.

Chapter 1

Research Question, Objectives & Methodology

1.1. Research Question & Objectives

The overarching research question for this report is 'How can Qatar best meet the educational needs of pupils with autism?" The four core objectives underpinning the main question are:

- to describe current access and quality of education provided to individuals with autism;
- to highlight the strengths and weaknesses of various interventions available to children with autism;
- to identify best policies and practice in implementing the NAP
- to formulate policy recommendations to improve the provision of education to individuals with autism in Qatar.

1.2. Methodology

The effectiveness of interventions, the extent of service needs, and the organization and delivery of services across health, social services and education are significant themes that need to be shared between community and academic partners in order to work towards outcomes that are more relevant to promoting inclusive practices for individuals on the autism spectrum (NAPC, 2003). This research therefore reviewed current autism educational practices, understandings and policies in Qatar by undertaking a contextual enquiry, which involved investigating conceptions of inclusive educational practice and provision in Qatar, drawing on international and national literature and policies. Additionally, the team undertook empirical research by gathering stakeholder perspectives to understand the views, perspectives and experiences of those who engage directly in policy, practice and provision. Ethical permission was granted before data collection through the robust procedures in place at University of Birmingham, UK.[3]

For the contextual enquiry, the general search strategy was informed by the overarching research question for this report. Five main databases were used: ERIC, British Education Index (BREI), ABI Inform Complete, Google Scholar, and the ISI Web of Knowledge. The search included both peer-reviewed empirical studies and reports, articles, guidance and case studies from professionals, practitioners, and children and young people with autism and their families. Articles were included if the primary author and/or the research was from Qatar or the Gulf Region and included autism and/or special needs education within the content. The search was restricted to English-language publications, as access to translation services was not available for reviewers.

3. Ethics number ERN_17-0258.

One of the specific and unique realities of Qatar is that the total population of Qatar is more than 2.5 million, while Qatari citizens comprise approximately one-eighth of the population (Al-Hendawi et al., 2017). In addition, ninety-nine per cent of the nation's population is urbanized, residing mainly in Doha and its suburbs as well the coastal cities and towns. Given this fact and coupled with the time constraints for this research, the study focused on gathering stakeholder perspectives from a range of participants primarily based in Doha. There are different provisions and opportunities available for Qatari and expatriate populations, and this was taken into account in sampling participants for the research.

1.3. Participants

We sought the views and perceptions of a range of organizations and individuals, in order to gain a holistic view of practice and provision for children with autism. We collaborated with the World Innovation Summit for Education (WISE) and the MoEHE in Qatar to find possible research participants. We also conducted an Internet search for relevant organizations in Qatar that we could invite to participate in individual interviews and focus group interviews. Our sample was purposive; interviewees were chosen who would give access to multiple perspectives relating to the focus of investigating current understandings, knowledge and practice for pupils with autism, within the themes of inclusion, legislation, policy and training.

We were conscious that participants should include both Qataris and expatriates. Altogether we consulted 69 people during fieldwork in Doha in March and April 2017, and a further two people were interviewed via Skype and email. Their input was invaluable and a list of the participant organizations is provided in the acknowledgement section of the report. One member of the research team was bilingual so that participants were afforded the option to communicate in Arabic, although most chose to speak English. An outline of the participants is given in Table One.

Category	Number
Parents and caregivers	11
Specialist providers	38
Mainstream government schools staff	2
MoEHE staff	6
Psychiatry services, Sidra	1
WISE	2
Researchers	2
Person with autism	1
University faculty	2
Islamic leaders	2
British Embassy	2
Charity staff	2
Total	71

Table 1: Breakdown of the stakeholders we spoke to.

1.4. Methods

Focus groups and individual interviews were semi-structured to allow for flexibility. They included questions designed collaboratively by the research team, and varied depending on the status of the participant. Focus groups were group interviews conducted by two members of the research team at a time in order to gather a range of views from a small group of people who had a particular role or perspective on the topic. Focus groups are a well-established method of data collection in social research studies (Cronin et al., 2008) and are considered useful in studies that require consideration of group processes (Punch, 2013). They provide a naturalistic setting that may encourage participants to provide more detail about their ideas (Schutt, 2011). This group interaction is also likely to help people to formulate ideas (Reed & Payton, 1997) or to develop aspects of the topic that might not otherwise have emerged (Babbie, 2010). As the researcher does not attempt to maintain an uninvolved stance, it is possible to encourage participants to expand on areas of interest to the study (Marshall & Rossman, 2011). The purpose of these group discussions was to empower the participants to share meaningful experiences, enabling us to generate detailed responses as well as a broad overview of key issues from a range of informants.

Individual interviews were also gathered to collect personal accounts related to key questions. Interviews are used in social research to collect data relating to interpretations of and feelings about experiences (Denscombe, 2010). Semi structured interviews allowed us flexibility to vary the order of questions to suit circumstances (Denscombe, 2010). We could ask more detailed questions,

and respondents had the opportunity to have questions clarified for them, with the researcher also able to ask for clarification if required (Schutt, 2011). Open questions were chosen to elicit rich narratives for both focus groups and individual interviews (see Appendices One and Two for the questions).

We ran a total of 14 focus groups and conducted nine separate individual interviews. All except two of the focus group and interview discussions were audio recorded with permission from participants. Most of these were transcribed in full although three were semi-transcribed and took the form of summary notes.

1.5. Analysis

In analyzing the data from the focus groups and interviews, we drew on the whole data set and used an inductive approach in which we went back and forth in our analysis of the data using thematic analysis as a method for 'identifying, analyzing and reporting patterns (themes) within the data' (Braun & Clarke, 2006, p. 6), We used a semantic approach to capture descriptions of the meanings of participants in relation to their experience of the sociocultural context (Braun & Clarke, 2006), and with a specific focus of answering our research questions. We adhered to Braun and Clarke's six-step process (Braun & Clarke, 2006). The first step was familiarization with the data. Four researchers worked together undertaking fieldwork, and after each focus group or interview, we had detailed discussions about issues and observations that were emerging. We also all took detailed notes.

In the second stage, three researchers transcribed a certain number of focus groups and interviews each. For the third stage, three researchers then read all transcripts in order to generate initial codes and to start the process of organizing the data into meaningful themes. The fourth stage involved three researchers searching across all data sets to find patterns of meaning in relation to the research questions themselves. These categories were then organized into themes in the fifth step, with each researcher then analyzing a third of the transcripts in detail. In the final stage, the researchers undertook a final review of the themes.

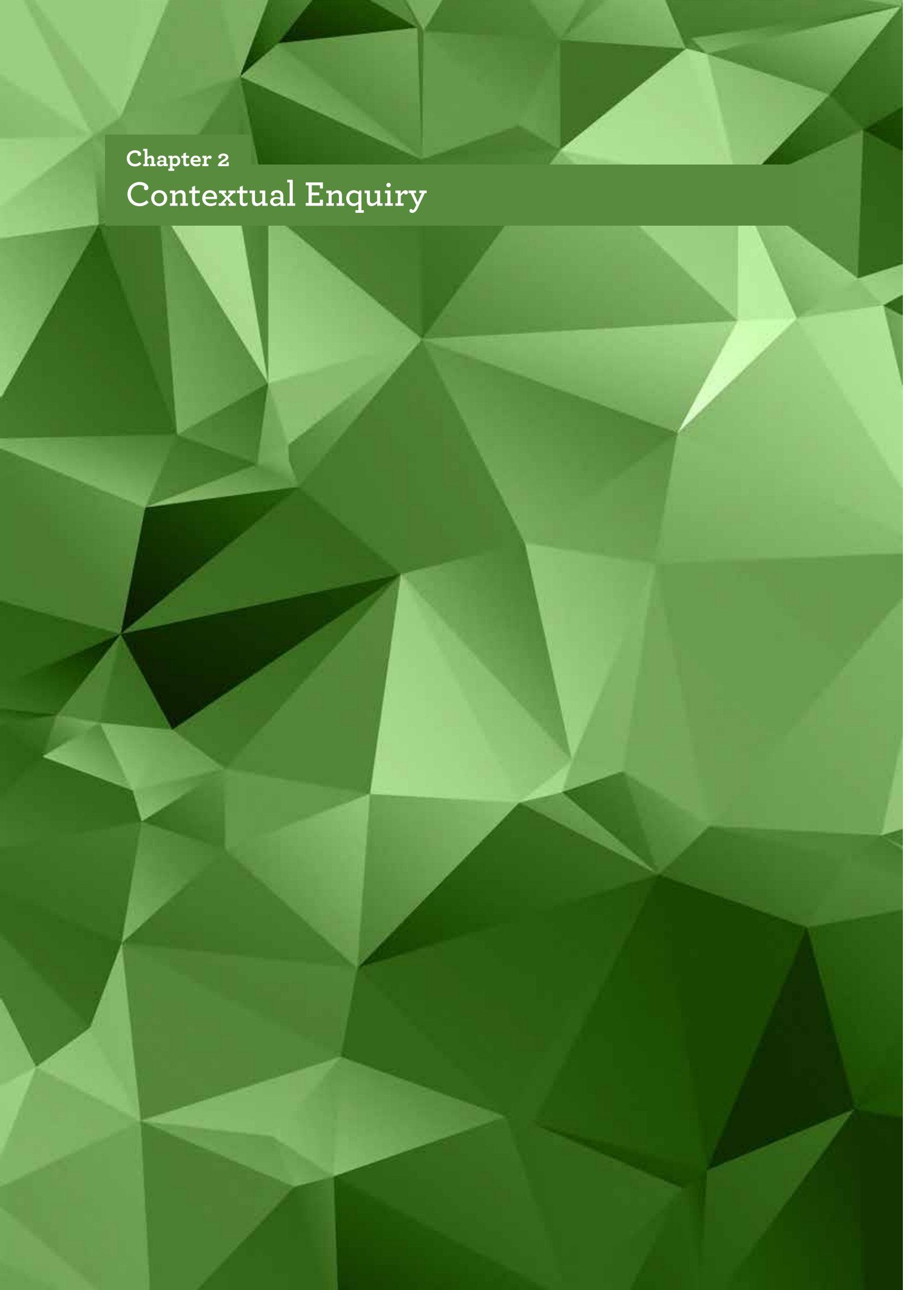
Through this rigorous process, each segment of data was given a code, and these were then organized into categories (such as 'comments on attitudes to autism'), and the categories were then allocated to themes, which represented major elements and higher level categorizations. The themes were carefully considered in relation to the key research questions, thus gaining clear participant perspectives on those research questions, and then by letting the 'stories' of the participants emerge through the themes. There were three key themes that emerged, each with a number of sub themes. These are outlined in the findings section.

1.6. Limitations of the Research

We wished to include the voices of children and young people with autism as we are fully committed to the involvement of autistic people in research and believe it is absolutely crucial to gain their perspective. Disappointingly, linguistic and cultural barriers made it difficult to identify individuals who would be willing and able to participate. However, we were very pleased to be able to include one young man with autism as an interviewee, but are aware that we do not have the perspective of autistic children with learning difficulties to draw on. We believe that incorporating the voice of autistic people is a crucial next step for further research in this area, as can be seen from our recommendations.

Our sample of participants was purposive because we wanted to gain the perspective of people who are at the forefront of autism provision and practice. The sample can therefore not be said to be representative of the population as a whole. It was not intended to be so as this was essentially a scoping study to understand the perspectives of people who are engaged in the field of autism education on the ground, whether as professionals or parents. Although we had a translator, cultural and language issues could mean that we might not have captured nuances. The cultural context was new to us, so we viewed the situation from the 'outside in', working hard to gain an understanding of realities. We nevertheless recognize that this understanding may at times lack the depth it might have had if we were undertaking research in a more familiar context.

Time constraints meant that we needed to stay very focused on what was possible within the timescales. The research team would also have liked to include more mainstream schools, both independent and private, in our inquiries, and we prepared a carefully designed questionnaire to be sent to all schools. In the event, however, this proved to be beyond the scope of what was feasible given the time constraints of the research period and the challenge of translation. The questionnaire could perhaps be a useful research instrument for future in-depth exploration of knowledge and understanding of autism in Qatar's schools.



Chapter 2

Contextual Enquiry

2.1. Inclusive Education

The contextual enquiry involved investigating conceptions of inclusive educational practice and provision for pupils with autism in Qatar, drawing on international and national literature and policies when relevant. This review includes examination of Qatar's policy on education in general, its relationship to UN conventions and its specific national development strategy addressing the education of pupils with disabilities, as well as the Human Development Outcomes of the Qatar National Vision 2030 (General Secretariat for Development Planning, 2008). It captures the strategies currently in place in Qatar, covering the range of provision offered to students with disabilities including children with autism, as well as the practices, resources and available training.

A recent report by the World Innovation Summit for Health (WISH) Autism Forum (Munir et al., 2016) found that children and young people with autism continue to face barriers accessing an inclusive public education in many places in the world, citing that children with disabilities represent approximately one-third of the more than 60 million children still excluded from public schools. This is significant given the move towards inclusive practice in education over the past twenty years and widespread agreement on the key principles first encompassed in the Salamanca Statement (United Nations Educational, Scientific and Cultural Organisation (UNESCO), 1994), which make explicit reference to the importance of ensuring inclusive systems of education and the rights of disabled children. These principles have been reinforced by legislation, policy, and recommendations at national and international levels, including the *UN Convention on the Rights of Persons with Disabilities* (United Nations, 2008).

The UNESCO definition states that inclusive education is: "an ongoing process aimed at offering quality education for all while respecting diversity and the different needs and abilities, characteristics and learning expectations of the students and communities, eliminating all forms of discrimination" (p. 3). This broader definition, encompassing universal involvement, access, participation, and achievement (Ouane, 2008), widens the context for inclusion from simply being a means of understanding and overcoming a deficit, to an ongoing process that has equal rights as its ultimate aim. It also extends earlier definitions that have often focused on the difference between inclusion and integration into mainstream schools.

The model of integration saw learners with AESN being placed in mainstream education settings with some adaptations and resources, but on the condition that the disabled person and/or the learner with AESN would fit in with pre-existing structures, attitudes and an unaltered environment (Alliance for Inclusive Education, 2017). This stands in contrast to inclusion, where disabled pupils and/or those learners with AESN are educated in mainstream education

settings alongside their non-disabled peers, where there is a commitment to removing all barriers to the full participation of everyone as equally valued and unique individuals (Alliance for Inclusive Education, 2017). The UNESCO Policy Guidelines on Inclusion in Education (UNESCO, 2009) set out clear justifications for working towards inclusive practices.

This change in understandings of inclusion has run parallel to the international community's commitment to human rights and has led to a reduced emphasis on an individual's disability: "inclusion may be understood not just as adding on to existing structures, but as a process of transforming societies, communities and institutions such as schools to become diversity-sensitive" (Arnesen et al., 2009).

The ideology of inclusive education, as outlined above, is nevertheless implemented in different ways across different contexts and varies with national policies and priorities, which are in turn influenced by a whole range of social, cultural, historical, and political issues. Therefore, inclusive education needs to be understood as a fluid process of "identifying, understanding and breaking down barriers to participation and belonging" (Guldberg, 2010). This shows that it may be useful to consider inclusion not as the binary opposite of segregation, but to recognize that a variety of forms of provision may be needed (Wittemeyer et al., 2011; Parsons et al., 2009; Hesmondhalgh, 2006), that special schools may be necessary for some children with autism and that they could be places of excellence (Hesmondhalgh, 2006).

Ravet (2011) makes the case for an 'integrative inclusionist' model that enables multiple rather than binary possibilities for the inclusion of autistic children and young people within education. She argues that the needs-based and rights-based perspectives on inclusion have come to dominate the field of autism education and provide contradictory standpoints on the effective inclusion of children and young people on the autism spectrum in mainstream schools. The 'needs-based' perspective highlights the lack of research evidence for mainstreaming autistic students and the risk of exclusion this may cause. Key to this perspective is the availability of a range of schools and educational provision to meet the distinctive group needs of autistic children who have identified additional support needs (Lindsay, 2007).

In contrast, the 'rights-based' perspective argues for no educational segregation and the inclusion of all children and young people in mainstream schools (Allan, 2008). This approach prioritizes the right of children to wide academic and social inclusion, and the requirement of schools and practitioners to adapt their practice to meet the needs of autistic students. The 'integrative inclusionist' model reconciles the two dominant perspectives, while acknowledging that neither has a "monopoly on the values of social justice, social democracy and social equality" (Ravet, 2011, p 679). This recognition of the need for a variety of understandings and forms of provision is reflected in the literature relating to inclusive practice in Gulf countries outlined in the following section, in which the 'mixed model' of inclusion refers to the mixture of private and public provision, mainstream and specialist.

2.2. Inclusive Education in the Gulf Countries

The international efforts to establish the rights of children with disabilities over the last twenty years have impacted policy and practice within the Gulf states. This has seen all Gulf states embrace the theoretical framework of 'Education for All' (Al- Khateeb et al., 2016) and accept a broader definition of inclusion. The result has been a proactive stance to improve educational opportunities and social inclusion for students with AESN, while increased public awareness and education programs have focused on wider awareness, understanding and acceptance of disability (Al Thani, 2009). Despite the move forward in inclusive education, the underlying disability context is nevertheless still predominantly medical rather than rights-based (Weber, 2012; Al Thani, 2009).

Most Gulf countries have policies and laws designed to enable the protection of the rights of disabled people and children, and young people with Additional Educational Support Needs (AESN) (Hadidi & Al-Khateeb, 2015). These include the right to special education, to be included into community life and to be employed. However, criticism has been levelled that over the past ten years national frameworks and committees established in Gulf countries rarely follow up on the implementation of those laws and procedures (Abu Alghaib, 2012). This situation has been further challenged by a lack of clarity from some states on the range of approaches needed, and the practical process for the enforcement of legislation. For some researchers, this has reinforced negative social stereotypes and attitudes towards children, young people and adults with disabilities and special needs.

Researchers have also highlighted that the medical and welfare model of disability still dominates (Al Jundi, 2013; Hagras, 2005) and leads to a widening between policy and practice (Watkins & D'Alessio, 2009). Though there has been a significant shift in policy towards inclusive education in many Gulf countries, (e.g. Kuwait, United Arab Emirates (UAE) and Qatar) the challenge remains in making this a reality for all children and young people with AESN in this region (Amr, 2011; Abu Alghaib, 2012). This is reflected in provision that is often still largely institution-based and segregated, except for special classes or resource bases within public schools. Hadidi and Al-Khateeb (2015) view this as parallel to the initial stages of a model of 'integration' seen in Europe and the US in the 1960s and 1970s.

Issues remain regarding the acceptance of individuals with disabilities by some aspects of society, schools, and families (Crabtree & Williams, 2013). This was reflected in the findings of a systematic review of research into inclusive education in the Gulf countries (Al-Khateeb et al., 2016). The results indicated that attitudes toward inclusive education by practitioners were generally neutral to negative, especially concerning the inclusion of children with disabilities. Some studies indicated more positive attitudes

though they also highlighted several challenges to effective inclusive practice within schools (Abu-Hamour & Muhaidat, 2013; Al-Manabri et al., 2013). These included a lack of staff training and support; large class sizes; a rigid curriculum; unsuitable learning environments and buildings; and a lack of specialist materials and resources.

Importantly, a major barrier to inclusive practice in schools relates to the lack of material on the perspectives of autistic pupils themselves. Article seven of The UN Convention on the Rights of Persons with Disabilities states that:

> *Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.* (Article 7.3. UN Convention on the Rights of Persons with Disabilities, 2008).

This right is not reflected in the literature, as we found no research studies drawing on the voice of pupils.

2.3. Policy & Practice in Qatar

The State of Qatar is a small sovereign country occupying 11,521 square kilometers on the eastern coast of the Arabian Peninsula. A period of rapid economic growth over the past twenty years, largely based on the extraction and exportation of natural gas and oil, means Qatar now has one of the highest per capita incomes in the world. This period of prosperity has seen a significant population increase for the country creating challenges in the development of infrastructure and services, while balancing the preservation of cultural traditions within a program of modernization (Al-Hendawi et al., 2017). Education has been at the forefront of these reforms and Qatar has positioned itself to be a leader in education amongst the Gulf countries (Al Attiyah & Lazarus, 2013). The wide-ranging changes initiated in Qatar's kindergarten through grade 12 (K–12) and higher education systems are described in the following section.

Qatar recognizes the universal rights of children and young people with special educational needs and disabilities through support of international legislation such as the *UN Convention on the Rights of Persons with Disabilities* (CRPD) (United Nations, 2008), ratifying it in May 2008. Within Qatar, the Supreme Education Council (SEC), the predecessor of the MoEHE, established an Additional Educational Support Needs (AESN) unit in 2009 to provide enhanced services for professional development, student assessment and parental support. This reflected the SEC ethos of inclusion with procedures aimed at supporting all students in learning and participating effectively in

the educational system. It recognized the rights of children with disabilities to fully participate in the classroom and the role the school must play to achieve this goal. As such, policy guidance (Supreme Education Council, 2009) was produced for independent schools in relation to their responsibilities for students with special educational needs and disabilities from kindergarten to secondary schools. This built on international policy and legislation such as the Salamanca Statement (UNESCO, 1994) and the *Convention on the Rights of Persons with Disabilities* as well as reflecting education laws within Qatar.

2.4. The Education System in Qatar

In 2001, the RAND Corporation was commissioned to redesign the country's education system, resulting in recommendations that Qatar initiate a comprehensive program of standards-based reform (Brewer et al., 2006). The Supreme Education Council (SEC) was established in 2002 to lead this process and focused on building a system based on the four key principles of autonomy, accountability, variety and choice. Work was done to establish internationally benchmarked curriculum standards in the core curriculum areas of modern standard Arabic, English as a foreign language, mathematics, and science. The educational reform process in Qatar has faced the challenge of integrating a model of inclusive education for students with special educational needs and disabilities within its structure. This was recognized in the *Qatar National Development Strategy 2011-2016* which identified the steps needed within special education to reach the educational outcome of the Qatar National Vision 2030 (General Secretariat for Development Planning, 2008).

As outlined in Table two, a range of schools and settings exist in Qatar (Brewer et al., 2006). In addition to these schools, Qatar has separate centers and specialized schools to educate children and youth with disabilities. As of the 2013/14 academic year private schools accounted for 59 percent of the 245,000 students in all of Qatar's schools (MoEHE, 2015).

Types of educational placement

- 178 Independent schools
- Separate centers and specialized schools- state run
- Separate centers and specialized schools- privately run
- Private schools that primarily serve the expatriate community and that include Arabic, Community and International schools
- Qatar Foundation schools
- Qatar Foundation schools specifically for pupils with special educational needs
- Pre-schools: government funded and private
- A government funded pre-school specifically for children with autism.

Table 2: Types of educational placements in Qatar

An administrative body, the Education Institute, was given responsibility for enacting the policies and developing a plan for students with disabilities within schools. In 2007, the Institute created the Additional Educational Support (AES) Department to help schools meet the needs of students with AESN and establish the program of AESN in the schools. Support for special education was further extended in 2015 to include the Special and Gifted Education Office in the MoEHE. The responsibilities of the AESN department were wide ranging and included: providing schools with evidence-based practices; enforcement of inclusive practice in all schools; and developing positive partnerships with parents (SEC, 2009). The guidance directs schools to use a team approach to support students; provide professional development programs and training for staff; recognize the support needs of parents; and use an educational rather than a medical model of practice (SEC, 2009). Both public schools and separate centers pursue special education approaches that are innovative relative to previous practices used in the country, such as: co-teaching (see glossary for explanation of this term), cooperative learning, the use of assistive technology, the application of behavior analysis, and school-wide positive behavioral intervention and support systems (Keller et al., 2016).

To meet the needs of children and young people with AESN including those on the autistic spectrum, the Education Institute adopted the response to intervention (RTI) model (RTI Action Network, 2011). Though there is no single, thoroughly researched and widely practiced "model" of the RTI process, it is generally defined as a three-tier (or three-step) model of school supports that uses research-based academic and/or behavioral interventions. The principle is that every RTI can provide a school-wide framework for efficiently allocating resources to improve pupil outcomes.

The program is principally a teacher led process, but may involve other professionals and services throughout the three tiers of support (Supreme Education Council, 2009).

Response to Intervention Model
Tier One The focus is on all pupils receiving quality first teaching to meet their needs. Pupils are screened on a regular basis to establish baseline measures for academic and behavioral progress. Those pupils identified as being "at risk" receive additional class based support during the school day. Pupils who do not make adequate progress at this stage are then moved onto Tier Two support.
Tier Two Pupils are given increasingly targeted and intensive support matched to their needs and rates of progress. The level of training of the professionals providing support at Tier Two may differ along with the frequency and duration of intervention. Generally, Tier Two support is provided in addition to the standard curriculum, often in small-group settings.
Tier Three Pupils are considered for more intensive support at Tier Three if there are still concerns regarding their progress after Tier Two interventions. This requires a comprehensive multidisciplinary assessment of the pupil's educational needs including the identification of any specific learning or developmental disabilities. At this Tier, individualized, intensive interventions are used to target the needs of pupils. This involves more intensive teaching methods and may mean the placement of the pupil outside the general classroom to meet his or her needs.

Table 3: The Response to Intervention (RTI) Model

An Individual Education Plan (IEP) team meeting may be convened to determine appropriate supports and services in special education if a pupil's educational needs cannot be met through the mainstream curriculum. The policy of AESN placed students with additional needs into three broad categories with the identification process focused on what additional educational support may need to be provided. Students with Learning Difficulties (SWLD), consists of two subgroups: Students with Learning Problems (SWLP) who have short-term difficulties in written and spoken language, mathematics, and other areas of learning. The other group, Students

with Specific Learning Difficulties (SWSLD) have longer-term learning needs in similar areas. Students with Disabilities (SWD) refer to a second broad category of conditions that impact on the learning of pupils in school and so require additional educational support needs. These include: physical disabilities, intellectual disabilities, hearing impairments, vision impairments and autism. The third group, Students with Behavior Problems (SWBP) display behavior that challenge their learning and the learning of others. Government figures from the academic year 2014/15 indicated that students with AESN made up two percent of the whole school population in Qatar (MoEHE, 2015).

These figures do not include the current numbers of children and young people on the autistic spectrum attending school, though an earlier study (RTI Action Network, 2011) produced data for pupils with autism attending specialist provision within Qatar. The results indicated that the total number of pupils with autism (<18 years old) identified as living in the state of Qatar at that time was 294. This was equivalent to 0.16 percent of the typically developing child population. Distribution by gender showed a bias towards the diagnosis of boys (81.3 percent) with most pupils aged between 5 and 11 years old (mean age is 9.4 years). These figures are in line with a later study of 179 children (Alshaban, 2012), showing the highest prevalence rate of autism was among the age group 7 to 14 years (61 percent) with a male/female ratio of 82 percent/18 percent. Distribution by nationalities showed that Qataris made up nearly half of the pupils with autism (45.6 percent) in the Ghoneim, Al-Okka and Al-Naimi study, with Arabic being the primary educational language (73.4 percent) compared to English (22.2 percent) (Ghoneim, et al., 2010).

2.5. Summary

International legislation to support the rights of children with AESN over the last three decades has clearly influenced inclusive policy and practice within the Gulf countries. Qatar has been at the forefront of this change having broadened the definition of inclusion and embraced the theoretical framework of 'Education for All'. Policy in Qatar has led to a mixed model of inclusion with the establishment of state and private schools for children with SEND, while implementing inclusive education in some mainstream schools. This led Shuaib Chalklen, the UN Special Rapporteur on Disability, to comment, that "there is a need in Qatar to consider the mainstreaming of disability" (United Nations Special Rapporteur on Disability, 2010).

Chapter 3

Findings: Stakeholder views

3.1. Themes & Sub Themes

Three overarching themes emerged from the analysis of the stakeholder data, and these were awareness, knowledge and understanding; policy, provision and practice and personal and professional development. Each of those overarching themes had a number of sub themes, all of which gave insight into important aspects of knowledge, practice and provision for pupils with autism in Qatar. In the next sections, we outline the main themes and sub themes. We illustrate some of the themes in the beginning of the particular section with a collection of quotes from participants. All quotes from participants are given in green to clearly indicate direct quotes. Direct quotes have been adjusted to make them grammatically correct. The subthemes related to awareness, knowledge and understanding are given in Table Seven.

Overarching Theme: awareness, knowledge and understanding	
Sub themes	Terminology, misconceptions and stigma
	Gaps in knowledge about child development
	Diagnostic processes and the experiences of parents
	The Islamic perspective
	Promoting autism awareness in Qatar

Table 7: the sub themes for awareness, knowledge and understanding.

3.2. Findings: Awareness, Knowledge & Understanding

I have not told my family because if I told them they will give me the pity look.

For us in Arabian culture this is a disorder that affects our boys more than our girls and we are very proud of our boys and ashamed to admit that we have a child with autism.

There is such a pressure on parents here for their child to be 'normal.'

When you say autism they think that the person wants to sit alone. Because in Arabic the exact translation is being lonely.

Our culture wouldn't like to have the child different from the others.

3.2.1. Terminology, misconceptions and stigma

Participants highlighted that there is still a long way to go to increase acceptance of autism in Qatar, including the need to challenge the use of terminology. One parent stated that he was working with the government ministers to instigate raising awareness through the media. This person also talked with a senior official about the need to change terminology such as 'disease'. A group of professionals from a specialist center reported that a word they hear a lot is 'normal', stating that: *there is such a pressure on parents here for their child to be 'normal.'* These professionals also highlighted that families may accept their child has autism, but they go on to say: *but I just want her to be normal.* This group also felt that families often thought their child would be 'cured' or would 'grow out of' autism. As indicated by a specialist provider: parents often ask: *'how long is it going to take?'* Parents would sometimes think that the child would need two years of services and early intervention and would then be fine, not needing any further intervention or support.

Despite positive changes in recent years, participants highlighted that misconceptions still exist about autism among both the general populace and the medical professions. A specialist provider informed us that one parent was told that autism was related to how many moles a child had on their body. Another parent reported that a doctor had told him that the measles, mumps and rubella (MMR) vaccine (see glossary for explanation of this term) causes autism. Staff at a specialist center also talked of a parent who was in tears after a doctor had told her that she had caused her daughter's autism by being a 'refrigerator mother' (see glossary for explanation of this term) and by allowing her to watch too much television. At a recent conference, a participant reported that *there were qualified doctors saying autism can be cured, or saying 'I can diagnose autism by looking at a child's body.'*

Staff at three of the specialist centers talked about the fact that electroencephalograms (EEG) (see glossary for explanation of this term) were often done, with the resulting conclusion by doctors that if there was no brain abnormality, then the child could not be autistic. Doctors would undertake brain scans of the child and would say the child looks 'normal' even though the staff in the specialist center could see quite clear signs of autism. They also felt that doctors were in fear of giving the diagnosis: *pediatricians are scared to tell the parents. We have pediatricians who tell the mums this is a delay and they will overcome it.*

Several participants told us stories of children and adults with autism being kept in their homes or rooms, never to leave the family home. One professional told us *there are older kids at home, kids we don't see.* A parent indicated that that there are cases of children with autism who are abandoned in places like orphan houses because sometimes their fathers or their mothers do not want them. Both parents and professionals felt that there was strong stigma attached to autism, despite recent developments, as stated by one specialist provider: *there is a stigma here. I have a parent who will not mention the word*

'sensory' and you're not allowed to say the word 'autism.' Another comment from a parent referred to autism as a 'hidden disability': *in our society, some people are not aware of people like my son. He looks normal and when he behaves differently, some of them get scared, they go away...sometimes in restaurants they change the table to be a little bit further away because they feel scared. They think that he may attack them.*

Some participants had a different perspective on the issue of stigma though. Two participants felt that there is a perception that Middle Eastern families are in denial and stigmatized but that this should not be described as stigma as family and religious values are accepting and inclusive. Families would rather the child be at home and safe. Furthermore, a diagnostician highlighted that a lot more parents are seeking assessment and he felt that this shows that *there is less stigma attached to an autism diagnosis.* Several participants thought that people were often more hopeful if their child received an autism diagnosis rather than a diagnosis of learning disability. They felt that it might be easier to look at the strengths of what autism offers because of the possibility of exceptional abilities, such as in music, and that families would be more likely to come forward if it was a possible autism diagnosis. Staff at two of the specialist provisions highlighted the need for an educational model in thinking about the needs of children with autism. They felt that a medical model dominated and that they wished to celebrate an educational philosophy and approach.

3.2.2. Gaps in knowledge about child development

In addition to stigma and misconceptions, lack of knowledge about child development was highlighted as an important issue to address by a number of specialists, and this was seen to affect the rate of referral for diagnosis. Hiring nannies to care for children is commonplace, both in the Qatari population and in expatriate families. Many professionals expressed that Qatari parents might often leave parenting to the nannies and one specifically expressed the view that *usually the nanny takes care of everything...most of the time they know more than the parents about the child.* The nanny then becomes the main contact for the child and she will do everything for the child. A group of specialist providers stated that nannies play an important role but are sometimes more anxious to keep their job than to be an effective proxy parent. To put it in an interviewee's words: *the nannies don't have the proper way of being with the child because they are afraid of losing their jobs, so if the child is upset or anything, they will do anything to keep them quiet.*

Staff at one specialist provider felt that parents knew very little about child development and they found that their parent training sessions needed to go back to the basics of how children develop before even thinking about giving input about autism. One member of staff commented that *when we did the workshops for parents we found they don't know about the different levels of development and how a child's play would develop, for example. I had a parent coming to Occupational Therapy who said 'why do you do that? I never*

play with my child'. One professional at a specialist center said that she did not think the general population has a good grounding in typical developmental milestones: *the children come here and are not talking at five. The parent says- the kids are fine- my brother wasn't talking at five.* She then added that if they do have a grounding in child development, there is often a relaxed approach of: *oh they will grow out of it, it'll improve, oh their older brother showed some of this.*

Red flags around delayed development are, therefore, not being picked up early. As a result, concerns about developmental delay are often not raised until the child is four or five, and it is often school staff that raise concerns. It was also felt that medical professionals did not ask about child development. One parent highlighted that: *when I took her for vaccinations, they did not ask about developmental milestones, so I was not alerted that L might have autism.* One specialist provider explained that they are the initial point of contact for 80 to 90 percent of the parents coming to them. Some would have seen a pediatrician who might have said that the child is potentially not meeting milestones. The parents would then come to the specialist provider and would often be in denial. Other parents were referred to the specialist providers from school. The parents would come for consultation and say the school had sent them, but they believed there was nothing wrong with their child. They would often ask for a report to say that their child is fine.

In addition to concern about general knowledge of child development, concerns were also raised about the number of languages that are being spoken in terms of the effect this might have on the children. One participant commented that *with the nanny culture, if there are four children there are four nannies, all from different cultural backgrounds.* The language used by the nanny might be Urdu while the family might speak Malay at home. Many different languages are therefore used and this could be challenging, especially for children with autism. One member of staff at a specialist provision mentioned that: *here they are learning Arabic and English and then their nannies speak another language as well.*

One provider highlighted that when testing in the mother tongue, the child did not respond as expected in the mother tongue. The child could not follow basic instructions, and did not respond to his name. Parents would cling to the fact that this was related to the language barrier, and it was often hard for them to understand that it is not just the language. A specialist provider highlighted that many of their children who start in kindergarten are not well grounded in any language, so that is another layer of complexity as the children have learning challenges of some sort. They do not have a good grounding in any language and suddenly they are asked to attend a school where they are expected to know English and Arabic and also, as one provider stated: *deal with whatever their learning challenge is.*

3.2.3. Diagnostic processes and the experiences of parents

Pediatricians are scared to tell the parents.

We have met people who are very much in denial, they don't want to admit it.

The mum was very defensive and said 'no no no', my child is just a little delayed. They (parents) are preventing them (children) from getting services because they are so scared.

The parent wants us to say that the child is perfectly fine. When we do an assessment a lot of parents fight against it.

I want TV commercial showing red flags, like if your kid is not developing pointing.

Parents and specialist providers informed us that patchy diagnostic services have led to a situation where most of the parents we spoke to took their children for diagnosis outside Qatar. Families talked about preferring to go to their home countries: *most families get their diagnosis abroad.* In fact, with the exception of one family, all the expatriate families we spoke to had travelled abroad for diagnosis. The diagnostic process was also clearly highly stressful for some parents. One said that *we were overwhelmed psychologically and emotionally.* Receiving a diagnosis was a frightening process. A parent informed us that: *when anyone said 'autism' I just burst into tears. It hurt. To have a different kid. Why? Why my child? If you ask yourself these questions, it is normal as a parent to deny.* This, in turn, would lead some parents to fear for the future and be concerned about what will happen to the child as he or she grows older. Much of this fear relates to the fact that parents were concerned that they could not find a school place for their child if the child had received a diagnosis. A specialist provider commented that *sometimes parents are so scared of the diagnosis that they say to the person writing the report, please only put that my child has ADHD, rather than say he has ASD, because he will be excluded from the school.*

The gradual development of diagnostic services, coupled with better awareness, has nevertheless led to more positive experiences for some parents. Although many parents had difficult experiences with the diagnostic process, there was also a clear sense that things are improving. Staff at the diagnostic units at Sidra Hospital and staff the Qatar Biomedical Research Institute (QBRI) indicated that money and resources have been put into diagnostic services and training doctors in recent years. At the Renad Academy, parents were openly saying that their child had autism. Similarly, at QBRI it was felt that parents who came there were not resistant to diagnosis. Participants commented that this might be because families attending the Renad Academy and QBRI have already reached the point of accepting that their child has additional needs and they feel well supported by these organizations.

Two parents who had accepted their child's diagnosis spoke of the journey they had had in coming to terms with their child's autism. They both expressed positive acceptance, pride and love as well as hope for the future. A mother commented that *I'm proud of my son, I love him. As a mother, I had never dreamt that at age 17, I would be able to travel with my son without issues. I never thought that he could stand in a line in a supermarket or that I could take him to a restaurant. He is not the boy I thought I would have, so I feel very satisfied. As a mother of a boy with autism I see a bright future. I am proud of him and want to change the way that autism is perceived and how society deals with children with autism.*

3.2.4. The Islamic perspective

Although one professional in a specialist center expressed the view that: *there is still the feeling that maybe this is God's punishment,* several commentators on the Islamic perspective, including a religious leader, suggested that there should be no stigma. This religious leader rejected and was saddened by the notion that autism might be seen as a punishment from God. He felt strongly that people should not feel ashamed of a child with autism and that autism should not be stigmatized, as this was not a true Islamic understanding. He felt that there is not much understanding of autism in society and that the mosque could help to promote autism awareness. Both the religious leaders we interviewed tended nevertheless to describe autism in medical terms, as a sickness or illness. One religious leader stated that Islam sees 'disease' and 'sickness' as something that people should accept and that communities should include and look after people who have autism. He also continued that: *for every illness, Allah provides a cure and so parents must continue to strive, with patience, to find the cure for their child as that is what God wishes them to do.*

Religious leaders expressed the view that God rewards those who look after someone who is sick or disabled, so by accepting their children, they become closer to him and they will become better Muslims. Both the researchers we interviewed felt that the key message is about motivating parents not to see this as a punishment, but that it's an opportunity for them to reap rewards if they stay patient. They stated that although there is not a specific verse in the Quran that tells you how to treat a child with special needs, there are general verses that cover the importance of treating others fairly and being patient so that you can reap the rewards in the hereafter. This does not necessarily mean that the message is that this is Allah's will, but that it is about the effort you put in to improve the life of your child. Several participants felt that raising awareness through Islam could enable easier rapport with parents and practitioners and could also be used as a way of strengthening understanding. One researcher suggested that: *one of the ways to move forward in autism awareness is really to leverage these Islamic teachings as families will seek religious perspectives to show them the right way.*

3.2.5. Promoting autism awareness in Qatar

Although many participants highlighted that there's a long way to go to change perceptions of autism, there was also a strong sense of pride amongst participants about the way in which Qatar has moved forward so rapidly in the area of disability. Participants talked about the fact that there is commitment among the leadership that this is something that should be recognized and talked about, with strong efforts being made to make sure the parents are not stigmatized. An example given was that it was initially Her Highness Sheikha Mozah Bint Nasser who proposed April 2nd World Autism Day to the United Nations (UN) in 2007. This strong and active support from the Ruling Family for disability rights was seen as one of the key reasons to why the NAP 2017-2021 has moved forward so quickly. Many participants valued this support from the Ruling Family and the Prime Minister, and were positive about the way in which stakeholders, including families and parents, had been involved from the outset.

This stands in contrast to the past when there were only a few centers that supported children and young people with autism. A strong theme to emerge from the interviews and focus groups was therefore that a lot has changed in the last five years in both recognizing the problem and admitting it. Positive changes include that there are now many presentations and symposiums on autism, as well as celebrations for World Autism Awareness Day (WAAD) (see glossary for explanation of this term). One teacher commented that there is now a conference every month. Another schoolteacher highlighted that you see a cross-section that is representative of the population at events like this. People were optimistic that positive change was possible, saying that Qatar has money and energy to make things happen and that there are dynamic young people to help to take things forward.

We move to the findings from the second overarching theme next, with sub themes outlined in Table Eight.

Overarching Theme: policy, provision and practice	
Sub themes	Post diagnostic services and support
	Schooling and inclusion
	Attitudes to special schools
	Qatari and expatriate differences
	Interventions and approaches
	Social and leisure activities
	Transition to adulthood

Table 8: the sub themes for policy, provision and practice.

3.3. Findings: Policy, Provision & Practice

3.3.1. Post diagnostic services and support

Families need support.

If a child is diagnosed with autism there is no clear answer or path for them to follow. This is the problem. There is no system that will support you.

Although detection of autism is better, intervention is still lacking and that is where families feel lost. Parents want help. Families need support.

It is very difficult. A diagnosis with autism doesn't get you anything here.

Here, they will give therapy if the child gets a diagnosis but it might only be half an hour once a week.

The majority of parents we spoke to highlighted a lack of support and insufficient intervention after diagnosis. Parents felt disappointed that the diagnoses of their child's autism did not lead to better services. Some reported that the autism program at the hospital only lasted ten weeks and for sessions lasting 30 minutes per week. All the parents stated that the sessions were too short and infrequent and some of them said that they were often cancelled. One parent reported that they were offered an early intervention program for *three months, including the diagnosis. Sometimes it was one hour a week or one hour every two weeks.* Others talked about only getting half an hour intervention per week, or even 15 minutes: *they say the sessions are for one hour but they last for 15 minutes.* This could be very difficult for a child with autism who needs extra time to get used to new people. It could also be very problematic pragmatically for parents. One parent had to take evening shifts at work from four to eleven in the evening to be free to take her child to the appointments in the morning, for example. She made the point that this is not good for her child because she was not at home in the evenings. Other parents talked about taking two hours of traveling to get 15 minutes of therapy, and: *there is little that can be achieved in 15 minutes a week.*

Many participants turned to the private specialist providers for intervention and support. All the parents we spoke to who had received support from specialist providers were highly complementary about the quality of this support. One parent explained that his *child had made incredible progress* after receiving input for three hours a week with a private provider. Participants highlighted that there had certainly been an issue in the past that there were not enough government funded specialist nurseries for children with autism, as stated by a parent whose son is now 17: *one of the problems in Qatar is that we don't have enough specialized nurseries and often they won't accept children with additional needs.* This was not enough to meet the needs of the

population, so there were long waiting lists. Most Early Years provision offered to children in general is private. One participant commented on this topic that *another thing that doesn't help is that the nurseries here are all private. They take any children. If the child has a need, they won't raise it. So the parent is comfortable having their child in nursery, but when he gets to four, the problems start.*

3.3.2. Schooling and inclusion

It is called inclusion but really the child is by himself.

I have had many parents crying, they are fighting constantly against school because they say 'your child is too difficult. We don't want to try and help so we're going to try to push you out'. And it is so hard getting another school.

And these children deserve to be in schools. I have one very high functioning child and I'm really concerned that he will not be accepted in school. With support, he can do the work.

More provision is needed, especially for severe cases. They should be admitted without parents having to lie [about the child's autism].

Staff are not trained for autism, shadow teachers have no training, the curriculum is inflexible and the environment is not autism-friendly.

The school will not take the child if they have a diagnosis.

We spoke to senior officials in the Early Years and Special and Gifted Education Administration at the MoEHE to gain perspectives on current policy and practice in Ministry schools, otherwise known as the independent schools. We discuss findings related to the independent schools separately from the findings related to private schools as there are different realities, possibilities and tensions in the different types of schools, with significant differences in provision for Qataris and expatriates.

A senior official informed us that there are 215 pupils registered with a diagnosis of autism in independent schools. Given that the prevalence rate reported by QBRI is 6 to 7 per 1000 for the low probability group (e.g. pupils in mainstream schools), and conservative estimates of the prevalence rate internationally is 1:100, this would indicate that there could be at least 2450 students with autism in all schools in Qatar as there are 245,000 students in total, so it would appear that there are many pupils who are either not diagnosed or do not attend school.

The Ministry officials highlighted that their vision is full inclusion. They said *we are looking for them to be in a normal life and take their education in a normal environment. The policy is for inclusion* and that as long as it's possible to teach a child and to adapt the curriculum, the child would be in mainstream school *because our first goal is for all our students to be in the mainstream schools.* A teacher from one of the independent schools argued strongly in

favor of the notion that all children with autism should be in mainstream schools. She maintained that children with autism tend to imitate the behavior of their peers and if inclusion is partial they will not have the chance to spend enough time with other children in order to *copy their behaviors, and improve communication, speech and social skills.* Ministry officials highlighted that although the overriding goal is for all children with autism to attend mainstream schools wherever possible, there is recognition that some children may not be able to cope. *'Severe cases'* will go to special schools and specialist provision.

When a pupil entered mainstream provision, they would start with 'partial inclusion' with the view to achieving full inclusion in the long run. We were told by the Ministry officials that partial inclusion means that the inclusion in mainstream class takes place gradually by working 1:1 with the child in a separate class first and then gradually placing the pupil in the mainstream class. One parent commented on this: *I tried through the Ministry of Education* (Ministry of Education and Higher Education) *to put him in a mainstream class and they recommended partial inclusion; to be in a different class for most of the day and be included for breakfast and PE.* Another parent questioned this notion of inclusion, wondering what exactly partial inclusion means. She maintained that pupils are included only during PE and break time and she wondered where the child is for the rest of the time. She stated that the pupil would be in the same school but in a different classroom and she did not see this partial inclusion as effective for the children.

The Ministry officials highlighted that policies are under review and the Ministry are working to understand the particular needs of pupils with autism. The plan is to designate some schools as 'inclusion schools' to be distributed throughout the country. As there are not enough specialist teachers, and there are challenges in training the workforce, they have now identified 50 schools that will be inclusive schools, so that they can focus on developing high quality inclusion in those schools. Those schools will have the resources and facilities to be inclusive and they will be geographically located in different parts of Qatar. Alongside these 50 schools, assessments will be undertaken in the Rou'a Centre. The Rou'a Center falls under the umbrella of the MoEHE in partnership with Rumaillah Hospital.

As indicated by a senior official, the focus of this center is currently on *preparing our specialists to do the assessments in future. We are working to have the license to train them with Rumaillah and Hamad hospitals, so we'll have a team in to do the assessments.* The Rou'a Center is there to meet the needs of private schools, public schools and for any parents who have concerns about their child. A senior official also highlighted that *we brought all people together to facilitate things for the child, for the parents, and for the school. Everything will be in one place, so parents will not have to travel far and take things to committees, with the process taking very long.* At each stage of the child's schooling (kindergarten, primary and secondary), the pupil will be reassessed to see if their needs have changed.

Pupils with AESN in mainstream provision would also be supported by staff who were colloquially described as 'shadow teachers' by most participants, although at Awsaj Academy, (a school for children with learning challenges and an outreach center that provides professional development services to the community) they used the term 'instructional assistants'. The official terminology is 'assistant teachers'. These support workers work with individual children. Their role is to support the child to be independent, but there were criticisms regarding how little support these shadow teachers have been given, as stated by one parent: *they would get a shadow teacher for the child and they would treat them like kids with learning difficulties. No intervention, no resources, nothing was provided.* A specialist provider highlighted that *what I hear anecdotally from parents is that those shadow teachers have no specialized training.*

There has also been wider criticism of their role, in that one specialist provider stated that the assistant teachers tend to do everything for the child: *the shadow teacher does everything for him, they even write the assignment for the child. Most of the time she is not trained.* Another parent made a similar point, stating that *they are thinking that by having someone sit beside their child, their child will be successful. Well, we know that enabling a child in writing everything for them or reading everything for them and so forth is not teaching them the independence skills that they're going to need as we launch them into adulthood.* The Ministry informed us that what often happens is that assistant teachers intervene too soon and they make children dependent. They have therefore established a system of penalties for assistant teachers if they intervene too soon.

Several specialist providers stated that international schools accept very few children with autism: *parents are not given the support they need and children are not given the services they need. Sometimes they are told to leave the school and find another place because they can't provide the services. Services are not up to the level they should be for inclusion in schools.* Staff in one specialist center stated: *historically in Qatar if a child has a diagnosis they don't even necessarily consider the child for the next stage which is admissions screening, so they wouldn't even get to present the child's level of functioning.* Staff at one specialist independent school expressed the view that a significant number of expatriate teachers are not at all committed to the notion of educational inclusion which Qatar is working to build and that a 'philosophical shift' is needed.

A teacher in a private school made the point that *she would like to be in a school that was more inclusive.* She felt that there are a lot of factors that act as barriers against being inclusive, as there are cost implications. When teachers come from another country to work in Qatar, for example, the school sponsors them, but it is very costly because they have to set the staff up. There is an assessment for most schools and the child with autism and/or learning difficulties will not necessarily pass that assessment. Alternatively, they might pass the assessment but need additional support. Parents are then asked to

pay for the assistant teacher and this is an additional high cost on top of fees. One expatriate family told us that they used all their savings to pay for therapy for their child: *we reached breaking point a year ago. Used all our savings. We came to Qatar for financial migration — not because of love of the desert and the sun. We came here because we could do better financially.*

3.3.3. Attitudes towards Special Schools

If a child's needs are deemed to be too severe, the two main special provisions are Awsaj Academy, which is now a special education school catering to a range of learning needs, and Shafallah, which takes students from mild, to profound learning disabilities. The Ministry also recently opened a kindergarten called Al-Hidaya for children aged four to six (and sometimes to seven). The Ministry officials stated that *we think we should prepare them, so that when they are ready, they can go to mainstream schools.* They are preparing schools and recognize the need to think about the physical environment of school.

There are nevertheless clearly capacity issues in having enough places for pupils with additional educational needs. Prevalence rates have led one parent to state that *Doha needs more centers like Shafallah…. at my son's time 1 in 10,000 had autism, now the number is 1 in 68. Specialist providers such as the Renad Academy, have had to turn so many down because they didn't have capacity.* Some parents expressed concerns about sending their child to a special school as they felt there was stigma attached to that: *they (people in the community) think that if a child is sent to a special school they will regress.* This parent also raised concerns that the child might develop difficult behaviors: *we did not want to take him to Shafallah because I was worried that he will develop behavioral problems there from interaction with other special children.* Another worried that his daughter's development would slow down by being in a special provision. A school teacher and a mother stated that a lot of parents are put off by specialist provisions, particularly when they are run in homes and do not look like schools.

Staff at the Teaching and Learning Centre (TLC) and the Renad Academy found that they had to have very difficult conversations with parents. When a child is in a Qatar Foundation school, parents want their child to remain in a Qatar Foundation school. They would view the Awsaj academy or the Renad Academy differently and might not want their children in one of those two schools due to stigma. Having said this we spoke to a young person with autism who went to the Awsaj academy and he said the following: *I learnt a lot of things: how to become a great person; how to make a positive impact in the world and change people's lives and make the world a better place. Also, more about how the world reacts to you, sometimes bad, sometimes good.* Although this young autistic man came from an Arab expatriate family he showed great fluency in English, which was the language he asked to use during the interview.

3.3.4. Qatari and expatriate differences

All the expatriates we talked to, and some of the Qataris, pointed out that there were differences between expatriates and Qataris. Expatriate staff in one specialist provision felt very strongly that not enough was available for non-Qatari pupils. They felt that pupils with expatriate parents did not have the same opportunities as those with Qatari parents as they could not afford the fees for some of the best provisions. A member of staff in a specialist provision added: *so if I should look five years, ten years down the road I would hope that our doors would be open to kids from all different nationalities and you would not have to be Qatari to be able to get in.*

Schools have Arabic speaking teachers and English speaking teachers for different curriculum areas and this seems to lead to a division of cultures between the two and hence a lack of shared ideas about ways of working. Staff at a specialist provision said that translating recommendations and tips for parents is 'a huge challenge' for any of the specialists, and they cannot be sure that they have communicated clearly. The cultural and language issues were also raised in relation to how school staff work together. One participant commented that in *most of the schools they teach Arabic and Islamic studies, heritage and social studies in Arabic. This is very important to focus on their mother tongue.*

The problem raised was that in each school, there would be two separate entities because the Arabic teachers would teach in their own way and to their standards whereas teachers teaching in English would teach very differently. The argument put forward was that it has to start with the leadership because in some schools the Arabic and the English staff never meet, or they may meet only for a staff meeting. Even in terms of administration, there is the Arabic admin and the English admin and they do not meet together, they meet separately. In suggesting ways of avoiding such divisions in the future, one participant suggested that *I think that we need to model that we are a school and it doesn't matter what our race is that we are all learning together.*

3.3.5. Interventions and approaches

There are children who can't go to nursery any more, are not accepted in school and are just floating around at home.

Early intervention services are just starting and need to be developed.

Each child comes with a strength. We try to find what that is and work with it.

One of the problems in Qatar is that we don't have enough specialized nurseries and often they won't accept children with additional needs.

Early intervention is offered to autistic children in the form of private specialist providers as well as government-funded kindergartens. These specialist providers largely offer therapeutic approaches. We visited six private provisions that offered early intervention and the majority of those used a form of behavior modification approach, with many basing their intervention on Applied Behavior Analysis (ABA) (see glossary for explanation of this term). As stated by one participant: *there is a movement in the Gulf countries to get more Board-Certified Behavior Analysts.* One private provider stated that their early intervention program uses ABA and visual, auditory and kinesthetic (VAK) (see glossary for explanation of this term) approaches and that in addition to this, children have Individual Education Plans (IEPs) that include daily living skills. The provider offers a structured day and a varied Early Years curriculum. Another provider stated that they have five speech and language pathologists and base their program on ABA, script training and the Early Start Denver Model (ESDM) (see glossary for explanation of this term). Their programs are individualized and include music therapy and horse riding. They also have two Snoezelen rooms (see glossary for explanation) and a movie theatre to train children with sensory issues to be able to sit through a movie.

A teacher at an independent mainstream school highlighted that they use ABA and follow a plan that is unique for each child. They do educational diagnostic tests (e.g. reading, writing) with the children in order to move them up to the next level. At the beginning of the school year they set goals with each child and this is the reason they like to follow one program. At a specialist educational provision for children and young people with learning difficulties, they stated that they use an eclectic needs-based approach, drawing on a range of interventions, including ABA and TEACCH (see glossary for explanation). They draw up behavior to work on, transition activities, and make modifications according to the needs of the child, with some pupils having more intensive teaching. At another special needs provision, the staff train parents in Portage (see glossary for explanation), as well as in different elements of ABA. They also provide family support services. Before they put together the Individual Education Plans (IEPs), they discuss the goals with the parents. They also have an induction day when parents can come with their children to see the services they provide.

A teacher at a specialist school made the point that they do not prefer particular interventions, but are highly committed to early interventions and use the Picture Exchange Communication System (PECS) (see glossary for explanation of this term) with children. They provide individual services for speech and language therapy (SLT), Occupational Therapy (OT) (see glossary for this term) and also have group services for art and sports. They use TEACCH, the Picture Exchange Communication System (PECS) and ABA and they provide services inside the center but also outside which means that they teach children basic skills (e.g. washing hands, or going shopping) at the center and then they take them out to practice these skills.

Specialists talked about the importance of developing good relationships with parents and working to understand the child's individual needs. They attached importance to working closely with parents and to understanding the goals and aspirations they have for their child: *we always communicate with parents what we are doing and why.* This included building strong relationships with parents and running parent training programs to share expertise with them. One participant stated that *we ask the parents their goals and information about their child. All the staff know the child really well and there is good communication between staff and parents.* They also worked to share strategies. One of the issues one of the specialist providers encountered was that they felt parents tended to *think everything can be fixed.* After two months, the provider highlighted they would have a review and the parents would come back and say *'but he won't have a conversation with me'.* It was therefore important to develop a therapy plan and say which objectives they were working on. Another provider echoed the notion that parents often wanted quick results and for the staff to 'cure' their child. She had to tell the parents to take it *'one day at a time'.*

3.3.6. Social and leisure opportunities

The young man with autism whom we spoke to was keen to have more opportunities to meet people*: I would like more opportunities to meet other people and I would like those people to be nice.* There were comments from parents in particular about the lack of leisure facilities for children with autism in Qatar. More specifically, one mother said that *in Qatar we don't have any centers with special trained people to look after. We don't have support from government financially. There is nothing there. The government should step in.* Another parent felt very strongly that *none of the sports facilities here are geared up for children with autism. No clubs will accept them. I am concerned about what will happen to him as he grows older.*

Other parents spoke of the need for social inclusion in terms of clubs and organizations that young people and adults with autism could attend: *I would love there to be government support for clubs with specialized staff. I want more social clubs where they can go, or sports clubs where they can go. They could give us a day when they can go.* There were parents who had positive experiences of gaining access to leisure facilities though. One parent stated that *I wanted to teach my son swimming because he wanted this a lot. I went to the club I am a member of (it is a family club but I have a personal membership) and I told them that I want to teach him swimming and he has autism. His energy has to be released through sports. They accepted him. They assigned him to a very calm Indian trainer who is very sweet and works very well with him. My son loves him so much and he now swims very well.*

3.3.7. Transition to adulthood

So it is very scary when you see that the cut-off age for many services is 16 or 17, 18, 21.

In the US and UK people with High Functioning autism go to the University or college, my son stays home.

The things I find difficult in my life are making friends and trying to communicate with other people. I really like technology and I decided that when I graduate I'd like to go to college and study more about technology and turn that into a job.

This is my child, so what are you going to do when he's 18 and there is no work for him? What are you going to put in place to make some industries, some training available for all children with autism to get job skills and life skills and be able to function in society?

I wish I could build a world for my son of acceptance, love, care and understanding. I want people to understand, on an airplane, at the supermarket, at the mall, at the play area, that a child may have autism and exhibit behavior that is not 'socially appropriate', and they will still be accepted.

Several participants, both parents and practitioners, mentioned that all the focus was on younger children with autism who were newly diagnosed and people tend to *forget that there are children and young people who are growing older.* One parent thought people were fearful of adults with autism: *I started feeling that people are afraid of seeing these older people with autism, especially with all the behaviors associated with puberty and sexuality and aggression.* At a certain age, there were few options available for people with autism. Specialist providers, parents and a young man with autism all spoke of the need for opportunities for education and social inclusion for young people moving into adulthood as there is little provision beyond the age of 21. They expressed concern that the NAP 2017-2021 is too focused on children.

A parent also talked about the importance of preparing people with autism for life skills and the world of work whilst they were still in school: *they can work with life skills, teach them about the rules. We are working with the Ministry* (Ministry of Administrative Development, Labor, and Social Affairs) *because children are in school until high school and we can give them training for work.* One parent spoke about her son's dreams about the future: *he is dreaming about going to the University, studying, having a car and driving, having a house and getting married.* Parents worry about what will happen to their children when they reach adulthood. One parent wondered *'is he going to be able to marry and live independently?'* as there are limited job options available for people with autism in Qatar. Continuing their studies can also be very difficult for a person with autism. A specialist provider who currently works with an adult with autism explained that he was very unlikely to get a place at University because he had attended a specialist provision even though he is very capable with technology. Another participant talked about a friend of hers who has a child with special educational needs and she is despairing because there is nothing in the community for her child.

People also highlighted positives. In one of the specialist provisions, Shafallah, there is a post-secondary vocational track where they try to equip children with AESN with skills. Qatar Airways collaborates with this provision to hire people with special needs and they now have a Qatar Airways production line. After the age of 16, students move on to rehabilitation, which focuses on preparing them to get a job and teaching them how to be independent. Staff there reported that they found more than 100 jobs in the last year. The students do the packaging for first and business class and they are paid for this work. The project is now developing further towards a more inclusive model and as a member of staff announced: *Qatar Airways is now creating a place to take all workers from Shafallah to work there for them*. Although some people with disabilities can work from the premises of Shafallah doing work for other companies, some companies also provide them with a 'real' environment to work in. Staff at Awsaj academy, a Qatar Foundation specialist provision, called for a vocational program for older children and young adults with autism.

We move to the findings from the third overarching theme next, with sub themes outlined in Table Nine.

Overarching Theme: personal and professional development	
Sub themes	Current expertise and gaps
	Parent advocacy and training
	The need for coordinated professional development and for locally appropriate strategies and resources

Table 9: the sub themes for personal and professional development.

3.4. Findings: Personal & professional development

There is a need for people to have access to approaches that have good research behind them.

There is a need to transfer specialist knowledge and practice in to schools.

There is a need for the Ministry of Education to have oversight of training programs. And there is a need for a strategic approach to embedding training so that it is ongoing.

There is potential for online resources and training to be useful.

We need to bring in more professionals and to have 'train the trainer' programs.

There is a need for shadow teachers to be better qualified and trained.

3.4.1. Current expertise and gaps

We spoke to highly qualified and knowledgeable professionals. The strong expertise that already exists amongst the body of specialist providers, parents and schools was striking. As one specialist provider said: *many well-qualified people are brought in from other countries.* The staff teams in the specialist centers were clear about how they assessed children, how they set goals to work on and how they worked as a team to enable the child to learn and develop. They had excellent understanding of pupils with autism, were sensitive to the needs of families and were clear about the approaches and strategies they drew upon and why they used these strategies and approaches. The Teaching and Learning Centre (TLC) is another strong resource, which is funded by the Qatar Foundation, and provides learning support for the special education department. It serves all of the Qatar Foundation Schools, except for the Renad Academy, because the Renad Academy operates on their own in terms of the specialists: *so we're a big group of people to service inclusive practices across Qatar Foundation Schools.*

In the private schools, for example, a lot of teachers have put in place visuals in the classroom because there is an English as Additional Language (EAL) presence. One teacher we spoke to highlighted that they use visual timetables. They put this in place for the EAL students but *they know this is also very beneficial for the students with autism.* Specialist staff understood the need to look beyond the behavior to try to understand the function of the behavior. One participant commented that *there is a function behind the behavior. There is no such thing as bad behavior.*

All the people we interviewed nevertheless highlighted the need to develop capacity further and increase understanding, knowledge and skills in special education. One parent stated that *there are limited people with expertise here and because of that they have waiting lists.* There was a particularly strong sense that there were substantial gaps in mainstream schools. One specialist provider claimed that *teachers do not know what autism is or how to deal with kids with autism in mainstream schools.* School leaders all said that their staff do not know enough about autism strategies, with one leader saying that *what for us seems like the basics is not the basics for many of the classroom teachers, they just don't have that training and background and context.* There was a strong sense among participants that professional and personal development is the real way forward. School staff told us that *teachers are thirsty. They often pay themselves to do training. If we created training programs, they would be more willing to accept pupils on the autism spectrum as there are a lot of good professionals in Doha.*

Members of staff in independent and private schools reported that they do in-service training for the interventions they need to use for specific children and that they need support with training on how to teach academic skills. A teacher in a private school stated that they have a number of pupils with autism in secondary schools that are coping, but they need more information

about how to deal with their learning needs. The Ministry recognizes the need to develop the capacity of schools to work with children with autism and that staff are not yet ready for this and need to be trained: *staff are not readily available here, especially staff with specialist qualifications.* There is therefore a new policy that all teachers who work with AESN should have a recognized qualification in AESN. Given that the Qatari population is quite small, and there is therefore a lack of capacity in terms of qualified teachers in special educational needs, the Ministry has sent committees to interview teachers in countries like Egypt, Jordan, Tunisia and Saudi Arabia. This has included finding teachers with skills and qualifications in special needs.

3.4.2. Parent advocacy and training

The parents we spoke to were strong autism advocates. One parent was considering taking legal action if the recommendations in the NAP 2017-2021 are not enacted: *we said we wanted better services for autism or we would take legal action.* Parents have set up Qatar Autism Families Association and are campaigning for better services. There are also strong community links both within the Qatari community and the expatriate community. The Qatari families all know each other and expatriate mothers talked about the importance of community too. Doha Mums have strong links on Facebook, for example, and represent the voice of the expatriate community. One parent's comment on the topic was that *things spread by word of mouth and there is a big community spirit here.*

Parent training was considered a priority: *educating the parents, I think, is the most important step* said one professional interviewee. Specialist providers found that parents are very open to advice and training. This particular specialist provider undertakes home visits to provide help and support in the home, e.g. for using visuals at home. They also help the nannies and other family members, including sibling support. There has been some generic group training for all parents but also individualized training to meet the specific needs of each family and child. Two of the parents we spoke to talked very favorably about these training courses: *we have parent training sessions. I really like the parent training sessions.* A representative of the Qatar Assistive Technology Center (Mada) emphasized the importance of parents learning from other parents: *this is why we have the parents' association and it is very successful. They have the know-how. Even other institutions and organizations ask them what they should do.* Given the reliance on nannies, participants highlighted the importance of involving nannies in parent training, as indeed the Renad Academy, the Child Development Centre and the Mind Institute do, for example.

3.4.3. The need for coordinated professional development and for locally appropriate strategies and resources

Participants reported that professional development is very disjointed. Providers are isolated and do not know where to go for information. There is no port of call for resources and information. Despite the widespread use

of ABA, they do not have an accredited body that trains in ABA in Qatar. A teacher in a private school reported that *some of us have come here with some training in special needs, and others have come without training in special needs.* They do not have that team around them to support them in the way that people often have in other countries. A private school teacher felt that they were getting things right in primary school, but she had concerns about whether they were doing enough in secondary schools to support students through the examination system. Participants were hoping that the NAP 2017-2021 would provide more coherence because no one seems to have an overview. The staff at the Renad Academy highlighted that they saw it as part of their brief to bring specialist centers together to share approaches and training.

Much of the professional development available is not necessarily adapted to Qatar and participants felt that they need training that uses people on the ground. Translation is something that specialist providers have been trying to navigate for years. One expressed the view that *it is not just training and presentations, it is written documents that we need to send home sometimes to parents, we struggle with translation.* Although translation can be outsourced or provided by professionals, it's difficult to provide sensitive and appropriate translation that is specific to special education. It needs someone who understands that field and context.

As the majority of families are Arabic speakers, there is recognition of the fact that it can be difficult to use the 'normal' or standard checklists and that there needs to be more development of locally sensitive resources in Arabic. A teacher at an independent school highlighted that she would like to see more suitable strategies and interventions that are specific to Arabic children with autism. Moving in this direction, there are local organizations and people who are developing resources for children with autism. Mada provides people with disabilities with technology to support their education, employment and independent living. They just launched a program that is the first Pictionary in the region that has the Qatari identity of a person with autism.

Mada also paid the developers to do an Arab version of Clicker 5 (see glossary for explanation). They had another project to develop PECS symbols that were applicable to the country e.g. a woman in an Abaya and a mosque. People with autism can communicate using pictures for mum or dad with people wearing traditional clothes, for example. They build their pictures from scratch in a way that reflects the local culture. It is an open-source project in which all developers are welcome to use and develop applications using these symbols. There was also recognition amongst participants of the need for culturally specific research into educational practice for autism: *we have specialists who are coming from different countries, we don't know if what we are doing is effective or not, we need to conduct a lot of research to see.*

In summary, we sensed exciting, productive and proactive approaches as well as passionate commitment to improving autism education. On participant stated *I feel there is an excitement in Qatar about moving forward for children with autism.*

Chapter 4
Discussion

4.1. General Points

The aims of this research report were to describe current access to and quality of education provided to individuals with autism; highlight the strengths and weaknesses of various interventions available to children with autism; identify best policies and practices in implementing the NAP, and formulate policy recommendations to improve the provision of education to individuals with autism in Qatar. The combination of the contextual enquiry and the empirical research provided us with rich data to identify gaps and provide guidance for moving forward. We nevertheless argue that this study represents an initial scoping study and that further rigorous research is needed, as can be seen in the recommendations we make.

The themes emerging from the empirical data are data driven but nevertheless align well with the aspirations outlined in the NAP 2017-2021 as we understand it (this had not been published at the time of writing this report), and with the themes identified in the World Innovation Summit for Health (WISH) report (2016) entitled 'Autism: a global framework for action' (Munir et al., 2016).

4.2. Awareness, Knowledge & Understanding

Findings from fieldwork indicate that Qatar's government and state-sponsored organizations, as well as non-governmental organizations, centers and schools are working hard to increase awareness within the country about different disabilities and about autism in particular. It is helpful that stories in the media and participation in internationally recognized disability-related events are increasing and have produced positive changes over the years. Cultivating a greater acceptance of children and young people with disabilities in society needs to continue through awareness campaigns and positive media coverage as there still exists social stigma and negative attitudes. Some parents felt that they needed to hide that they have a member of the family with autism as they feared negative reactions and effects.

Parents, therefore, understandably tended to 'wait and see' in the hope that their child will outgrow their disabilities. One of the strengths of Arabic culture and families is that cultures and families can be more tolerant of behaviors that in Western societies would be seen as 'abnormal' (Alnemary et al., 2017). Family ties are crucial and tradition still governs social life (Al Thani, 2009). This family and community oriented way of life is very different to the individualistic nature of most Western societies and can lead to a strong belief that people take care of their loved ones rather than delegate that responsibility to government. Such a tightly knit extended family structure should be respected while finding ways of supporting parents to recognize

when their child might be showing signs of developmental delay, so that the child and family can receive appropriate support. Given the gap in the awareness among many parents about child development, a way of ensuring earlier diagnosis and recognition of a child's difficulties would be to focus on campaigns that increase awareness of child development as well as the ability to identify when there might be learning or behavior difficulties.

Our findings highlight that although there has been positive change in the last five years in relation to awareness of autism, it is vital to consider how to continue increasing the awareness of autism and acceptance of people with autism in the population more broadly. In this endeavor, we would argue that a philosophical shift is needed towards seeing autism as a different way of being, and giving a different perspective on the world, rather than presenting it as a disorder, a deficit or a disease. This orientation sees autism as a transactional condition that requires mutual adaptation on behalf of the person with autism and those who live or work with that person (Jordan, 2005; Prizant & Fields-Meyer, 2015). It makes it necessary to move away from language which presents autism as a deficit or an illness towards a language in which autism is presented as a different way of being; from a lens which overly focused on the difficulties and 'problems' presented by pupils with autism to a lens which looks at the strengths of people with autism; and finally but certainly not least, moving towards a world where the perspective and voice of people with autism is heard, and towards an integrated approach which combines a rights and needs based approach.

This approach to understanding autism has real implications for how to support parents and educationalists to enhance how they care for or work with the pupil with autism. Such a transactional model focuses on human rights, and disability as being part of diversity, with difficulties arising from an interaction between the individual and the environment (Prizant & Fields-Meyer, 2015). As a consequence, rather than viewing autism as an impairment, in which the difficulties are located within the pupil (Hughes, 2000), practitioners learn to focus on the relationship between the person with autism and those around them. It puts those who care for and work with individuals with autism in a position in which they need to be thinking about what they can do to change their own practice.

Such an approach emphasizes that interventions and approaches need to be bespoke, contextual and responsive to individual needs, emphasizing the importance of focusing on the individual child and adapting the environment to their needs. It is therefore vital for practitioners to listen to and act on the perspective of individuals with autism (Charman et al., 2011), to focus on the individual (Wittemeyer et al., 2011); work in partnership with other professionals and families (Wallace et al., 2013) and create enabling environments (Guldberg, 2010). There needs to be clear communication and transfer of information at transition times (between pre-school and school, between primary and secondary schools and between secondary schools and into adulthood). It's also important to focus on social progress and offer

positive behavioral support (NICE, 2013). School and other professionals should make extensive efforts to ensure that autistic students have a say over the decisions that ultimately affect their lives, especially at key transition points. Having their voices heard is crucial to empowering autistic pupils, especially since they are so disenfranchised throughout their lives.

An important consideration going forward for both policy makers and practitioners is to take onboard new research on gender differences in relation to types, ranges, severity and development of autistic spectrum characteristics in girls and women (Sedgewick et al., 2015). This has shown evidence that specific cognitive skills and learning styles may vary by gender in intellectually able autistic adolescents. For example, while boys are likely to show superior attention to detail, visuospatial skills, and inhibitory control, girls have higher skills in information processing, multiple conceptual tracking, divided attention and cognitive flexibility (Rubenstein et al. 2015). Furthermore, a study by Lai and colleagues (2015) found that in comparison with autistic males, women and girls on the autism spectrum show better expressive behaviors alongside different manifestations of friendship problems.

However, many girls are never referred for diagnosis, as their autistic traits are unrecognized, hidden by masking or unrecognized due to male stereotyped expectations (Dworzynski et al., 2012). Research in both the UK and US confirms that girls are significantly less likely to be diagnosed with autism than male peers with similar levels of autistic traits (Baldwin & Costley 2016; Cheslack-Postava & Jordan-Young 2012). Greater recognition, understanding and awareness of gender difference is therefore needed to provide effective early identification, diagnosis and support for girls on the autistic spectrum. More evidence on what types of provision, intervention and practice are most valid and effective for autistic girls will enable them to access specific education, social, health and community services to meet their needs.

4.3. Policy, Provision and Practice

There is a need for more accurate and reliable data on the size, scope, types and prevalence of disability, as this is fundamental to developing appropriate services and programs and in order to meet needs (Al Thani, 2009). Although there has been a steady development of services in Qatar, further efforts are nevertheless clearly needed to overcome the gap between policies, laws and the situation on the ground. The provision of post diagnostic services and an appropriate range of educational provision need to be prioritized. We were informed that there are 215 diagnosed children with autism in independent schools, but figures do not appear to be available regarding the number of pupils with autism in other schools. As these numbers are not aligned with projected prevalence rates, there are indications that there could be many children with autism who are not attending school at this time and may not be receiving an education. Although we do not have clear data to indicate this, this conclusion corresponds with the findings by Al Hendawi et al. (2017) that enrolment rate reported by UNESCO are in the 90 percent range in Qatar. Many of those ten percent who are not attending school may well have disabilities.

Several researchers have identified the barriers to successful and sustainable implementation of inclusive education to the school system in Qatar (Al-Hendawi et al., 2017; Al-Kaabi, 2010; Weber, 2012). At a national level, the lack of comprehensive assessment and graduation data for students with AESN makes strategic planning and accountability more challenging for these children. Without this information, it is difficult to determine if all children and young people with AESN are attending school, the type of educational setting they are attending, and what progress they are making (Al-Hendawi et al., 2017). This is important given the increase in the nation's population. It makes capacity building a significant issue in providing suitable educational provision and services. Government data (MoEHE, 2015) suggests that this may be a challenge for staff in both Arabic and International schools.

The need for increased capacity in such service options is noted in the *Qatar National Development Strategy 2011-2016*. In 2015, special education services in the country were further expanded and are managed by the Special and Gifted Education Office in the MoEHE. State-sponsored and privately run schools, centers and programs are being developed to expand the capacity of special education in the country (Al-Hendawi et al., 2017). The establishment of Rou'a center is an example of this as is the opening of the Al-Hidaya kindergarten for children with autism. Our findings nevertheless highlight the continuing need for expansion of special education services in the country, from early years through to adulthood. This needs to address the issue of costs in private centers and schools, particularly for the expatriate population, as feedback from our parent groups indicated very clearly that costs have been highly prohibitive to them in accessing services. The costs associated with private centers and schools make accessibility and quality a challenge for those who cannot afford such personalized care.

In addressing transition to adulthood, a number of barriers exist that limit the potential of social and educational inclusion. There is a two percent employment quota for employing individuals with special educational needs, but this is neither monitored nor enforced (Al-Hendawi et al., 2017). Students who do not graduate from secondary schools with regular diplomas do not satisfy the secondary school graduation criterion that is required for admission to the universities in the country. The broader issues of disability rights, employment and family support have been identified by several researchers as significant factors impacting the effectiveness of both social and educational inclusion in Qatar (Kay, 2011; Kheir et al., 2012). Al-Kaabi's report on special needs and inclusive education in Qatar in 2010 found that:

> *Central to the problem of the education framework is that there are no clear strategies for systematically providing families with information about the rights of their children, the goals of the educational programs, and the change process in order to effectively engage and advocate for their children* (Al-Kaabi, 2010).

4.4. Personal and Professional Development

One of the biggest challenges facing Qatar is the large increase in the population coupled with a shortage of qualified personnel in autism education (Al Attiyah & Lazarus, 2013). The development of services that are designed around the person, that focus on close partnership with parents and links with other professionals, and that value individuals with autism themselves, their parents and other family members, require highly skilled and knowledgeable professionals (Parsons et al., 2011). It is clear internationally that personal and professional development is a priority in the development of good autism practice in education as several research reports have highlighted a lack of staff training as a key barrier to good outcomes for children and young people with autism (Charman et al., 2011; Parsons et al., 2009; Wittemeyer et al., 2011). Our findings confirm this and highlight the pressing need to increase the awareness, knowledge and skills of the educational work force and to improve the capacity of educational settings to meet the needs of children with autism in Qatar.

Within schools in Qatar, there remains a challenge in recruiting and retaining qualified and experienced practitioners who can support the needs of children with AESN, leading to an over-reliance on the recruitment of specialists from other countries. This highlights the importance of investing in further faculty development for training teachers to become specialists in teaching students with AESN (Keller et al., 2016). Teacher education in Arab countries is not based upon a set of professional standards for practice, which would seem to indicate that a case could be made for developing a system for licensing, and to develop a set of professional standards for practice. The Special Educational Needs Bachelors and Masters programs at Qatar University aim to equip more students and give them skills to work in special needs centers so that they can become better qualified. One of the purposes is to target the Arabic speaking educators and to serve educators in the public schools. We have received very good feedback about these courses from two participants who completed the Masters program. There is a strong case for extending these courses so they also serve educators in private schools and to develop autism modules within the current broad disability focus, while encouraging a greater uptake of students as there is currently limited capacity to meet the demand for all special education teachers in the country, especially as the number of special education schools and programs increase.

Our participants highlighted that specialist providers are delivering good training programs for parents and other professionals, but that all training would benefit from strategic development focused on coordination and coherence. There is also no system of formalized training for assistant teachers who support many of the children with AESN in schools. More systematic, formalized training is needed for the many assistant teachers who support special education in Qatar. The policy objective of Qatarization is

to provide 50 percent or more of Qatari citizens with meaningful permanent employment while simultaneously fostering younger Qataris in order that they too may eventually benefit from this pioneering initiative. We recognize the importance of training and educating the Qatari population in order to sustain change.

As Qatar is a country of many languages in addition to Arabic, this presents a significant challenge for sharing knowledge and understanding. Many specialists do not speak Arabic. This can present a barrier to sharing knowledge in relation to autism and good practice in the education for children with autism, a field where there is a need for careful attention to the nuances of language. We would argue that it is a priority to attract truly bilingual or multi-lingual specialists to the field of autism and education, who can skillfully navigate between one language and another conveying equivalent meanings between the two. This is an important consideration, for example in training, in communication between school and home and in knowledge sharing between different stakeholder groups. Schools need people who are bilingual in order to address the division and separateness of English speaking and Arabic schools.

The lack of special education policies and resources contextualized to be meaningful and relevant to the needs of the population in Qatar is an issue for schools (Keller et al., 2016). The policy of inclusion, which some have suggested is based on Western ideas of social justice, might be more successful in Qatar if it draws its moral authority from Arab and Islamic values and principles about how people should be treated (Al-Hendawi et al., 2017). Educational materials need similar treatment. Some good examples exist, such as the development of resources by the Qatar Assistive Technology Center, but more needs to be done to establish policies, practices, and materials that are appropriately contextualized to Qatar. Assessments require not only linguistic but, at times also cultural translation, with norms suitable for Qatar and a greater number of personnel who are trained in their use (Keller et al., 2016). Although borrowing or translating into Arabic can offer temporary solutions, it is unlikely to be sufficient over the long run (Keller et al., 2016).

In order for the mixed inclusion model to succeed, there needs to be similar investment and standardization of policies across the different types of schools, whether these are independent or private. In order for a 'mixed inclusion model' and an 'integrative inclusionist model' to be successful, there is the need to establish a national program of continuing professional development in autism for all teachers and support staff in *all* schools, whether independent or private. Firstly, to ensure that all learning environments and pedagogies in mainstream schools are adapted to enable learners on the autism spectrum to participate and succeed in both academic and non-academic areas. Secondly, that good autism practice could also benefit other mainstream students without lessening the importance, or impact, of strategies for autistic students. This would mean the renaming of pedagogies

from 'special' to 'distinct' (Jones et al. 2008) to recognize they are not just for children with AESN but are also different, based on knowledge and understanding of autism. As part of this process, we recommend a strategy of identifying 'autism champions' in schools, who have in-depth training in autism, and who can go on to train other staff and become instrumental in cascading knowledge.

In short, the evidence from both the contextual enquiry and the empirical work highlighted the need to develop a framework for professional and personal development, from awareness and ascending to higher level accreditation. Standards and quality indicators should also be considered in order to help practitioners evidence quality skills and provision (see www.autismeducationtrust.co.uk for an example of these in the UK). There are high levels of dedication and skills in the existing workforces but greater collaboration can enable interdisciplinary teams to work together in a coordinated way to develop online information resources that raise awareness; coordinate national training programs for parents and all schools staff and enhance provision at university level.

There are strong examples of ways in which culturally relevant solutions have been developed through collaborative public-private partnerships in different parts of the world. In Queensland, Australia, for example, the autism Cooperative Research Centre supports industry led collaborations between industry, the community and researchers and focuses on autism across the lifespan. Their brief is wide and includes running a range of research programs, developing resources for people on the spectrum, delivering training and running a range of projects (www. autismcrc.au). In the US, the National Autism Leadership Collaborative brings together state level leaders from a number of US states to strengthen state leadership and improve system-wide capacity to improve outcomes from autistic people. The Ohio Center for Autism and Low Incidence (www.ocali.org) works with a number of partners to deliver a number of services, including certification and outreach. In India, Action for Autism and their National Centre for Autism, India, have spearheaded a number of collaborations with researchers and industry, including the establishment of a research site in India. In the UK, the Autism Education Trust partnership developed its professional development program in England. This partnership gathered key sectors of the community to collaboratively develop a three-tier process of inducting education staff in their knowledge and practice of autism. National Standards are interlinked with these tiers of professional development and were created to enable whole school development through establishing the key factors common to good practice for pupils with autism and to also facilitate self-evaluation for schools. A Competency Framework sets out the key understandings and knowledge required by staff working with children and young people on the autism spectrum. This provides a framework for staff to audit their own skills and to identify any gaps and professional development needs.

In Qatar, the continued development of local networks that involve people with and without autism, families and caregivers, and a range of professionals, both Qatari and expatriates, in a focused way, will be crucial in moving forward in a collaborative way, with stakeholders and autistic individuals centrally involved in the change effort. While the way forward for Qatar needs to be locally and contextually meaningful, and should be based on researching the specific and unique realities of Qatar, there is a lot to learn from good practice in other countries, particularly in relation to collaborative approaches that aim to bridge the gap between theory and practice and that harness the energy, experience and competence of a variety of sectors, including industry, education, health and social care. The continued development of local networks in Qatar will be crucial in moving forward in a collaborative way, with stakeholders and autistic individuals centrally involved in the change effort so that solutions can be generated from the community itself in a way that will create sustainable solution to transform autism education.

Chapter 5

Recommendations

Rich data that emerged from the stakeholders and the key findings are summarized below under the heading of 'the current situation'. The 'future vision' draws on the contextual enquiry and international literature to present what to work towards, while the 'opportunities for action' are the recommendations emerging from the gap between the current situation and the future vision.

We have not suggested a timeline or schedule for how and when to implement the recommendations as this is a local issue and we are aware that many changes are already being implemented in Qatar. We would, however, point to the advice of our valued reviewer, Professor Liz Pellicano, when she highlighted that although many of these recommendations might happen in parallel, it is paramount that the recommendations related to policy, provision and practice are prioritized, as it is crucial that families and caregivers have access to effective support through the diagnostic process and post-diagnosis, and that requisite educational support is available.

We recommend that a cross-ministerial committee is set up to oversee development of provision and policy and that a collaborative partnership consisting of a number of organizations from the public, private and third sector is funded to oversee and implement the recommendations related to awareness, knowledge and understanding and personal and professional development. People with autism and their families should have representation on the board, alongside stakeholders and key professionals.

5.1. Awareness, Knowledge and Understanding

Findings: the current situation	The future vision	Opportunities for action
Terminology used by some stakeholders included words such as 'normality', 'illness' and 'disease'.	*Autism is presented as a different rather than a deficient or disordered way of being and is no longer portrayed as an illness or disease.*	*Awareness campaigns focus on autism as a different rather than disordered or deficient way of being.*
There are misconceptions about autism.	*There is greater understanding of autism in society and autism is not seen as something which needs to 'be fixed' or cured. The strengths of individuals with autism are celebrated.*	*Knowledgeable professionals, autistic individuals and parents deliver coordinated training programs that challenge misconceptions and enhance awareness of autism.*
Parents and families feel stigmatized.	*Islamic teachings around care and acceptance are leveraged so that families can draw on the religious perspective to increase their awareness, understanding and acceptance of autism.*	*Work is undertaken with key religious leaders to challenge conceptualizations of autism as illness and to discuss how to leverage Islamic teachings in raising awareness of autism.*
There is a lack of knowledge about child development.	*There is increased awareness among all parents regarding child development. Key information about red flags related to developmental delays is readily available.*	*Awareness campaigns build on international examples of good practice in cascading knowledge about child development, and about red flags in particular.*
There is a lack of clarity about the meaning of 'inclusion' and a lack of shared commitment to inclusive education.	*Inclusive education is widely understood to be about good education and working to meet the needs of all children.*	*Knowledge about inclusion and inclusive practices for pupils with autism is embedded within all professional development programs. These take into account the perspectives and wishes of children with autism, as well as their families.*
There is a gap in research that captures the views and experiences of children and young people with autism of their educational provision.	*Research captures the views and outlook of young people with autism and is used to deepen understandings of autism, in the public, and amongst educational staff.*	*Research is commissioned to gather the views and experiences of children and young people with autism and this research is used to inform professional and personal development programs in education.*

Table 10: Findings, future vision and recommendations emerging from the awareness, knowledge and understanding theme.

5.2. Policy, Provision and Practice

Findings: the current situation	The future vision	Opportunities for action
Parents feel lost post-diagnosis and are not provided with the services they need.	*There is a supported pathway up to and including pre-school for both the Qatari and expatriate populations.*	*The MoEHE and the Ministry of Public Health work together to mandate post-diagnostic support and early intervention provision.*
Post-diagnostic support and early intervention is patchy, while pockets of excellent practice exist.	*There are effective intervention and training programs to train staff to provide post-diagnostic support and intervention.*	*A strategy for developing training programs for health and therapeutic staff are implemented and the number of professionals offering post-diagnostic support is increased.*
There is not enough data to inform educational provision.	*All pupils with autism are educated in settings that are appropriate for them to optimize their learning, development and wellbeing.*	*Educational planning for pupils with autism is based on prevalence rates and an appropriate range of provision is developed for all pupils and young people with autism.*
There is stigma attached to special schools.	*Parents and pupils with autism will have access to a range of potential provisions to meet needs, according to what is most appropriate for the pupil and their family.*	*Celebrate the work that takes place in special schools and consider drawing on the expertise of staff in these schools to develop further specialist provisions attached to mainstream schools.*
Teachers and schools need more tools and good professional development to help them provide a differentiated curriculum and pedagogy that takes account of the specific learning needs of pupils with autism.	*Teachers will be highly skilled in providing a curriculum that captures the learning, social, emotional and communication needs of all pupils with autism. Schools will use National Standards in autism education to enhance their provision.*	*The MoEHE work with researchers and stakeholders to develop a progression framework that is relevant to Qatar alongside a set of National Standards for settings and a Competency Framework for practitioners.*
There is a lack of social and leisure facilities.	*Social and leisure facilities for individuals on the autism spectrum are extended, and staffed by people who have an understanding of autism and who are willing to make appropriate accommodations.*	*Identify a range of centers, social and sports activities that will accommodate the needs of individuals with autism. Provide staff at those centers with training and support.*
There is little for young people after they finish schools.	*There are more vocational centers, housing, further education and college opportunities for older pupils, young people and adults on the autism spectrum.*	*There is policy collaboration between the MoEHE and the Ministry of Administrative Development, Labor and Social Affairs to develop a strategic and holistic approach to vocational training, housing, further education and college opportunities for young people and adults with autism.*
There is little support for transitioning into adulthood.	*There is support for children and young people with autism as they transition between educational stages and provisions, and as they transition into adulthood.*	*Ministries collaborate to develop strategies for supporting transitions between stages of schooling and provisions.*
There is a lack of knowledge about how many children and young people with autism attend different early years and school provisions, and where the gaps are in provision.	*There is knowledge about the range of provisions and places available for pupils with autism across all school sectors in Qatar, with detailed data about prevalence rates so that planning is in place to provide the appropriate provision.*	*A full-scale scoping study is commissioned to identify the range of provision available across private and public sectors, with identification of existing gaps.*
There is a lack of knowledge about which approaches, interventions and services are most appropriate for children and young people in Qatar.	*Rigorous research underpins provision and practice, and this includes evaluation of current practices.*	*Culturally sensitive research is commissioned to evaluate current provision and practices for autistic pupils and to capture local understanding and knowledge, including the most appropriate good autism practice for the local context.*

Table 11: Findings, future vision and recommendations emerging from the policy, provision and practice theme.

5.3. Personal and Professional Development

Findings: the current situation	The future vision	Opportunities for action
It is difficult for parents, staff or individuals with autism to find information and resources to help them access support.	*All parents and staff will have access to information, resources and support according to their needs.*	*Develop an online portal with information about autism and the evidence base for approaches, information about services and support organizations, and a range of practical resources to support parents, teachers and individuals with autism.*
There is lack of knowledge about the range of interventions that are available for pupils with autism.	*There is widespread knowledge about evidence-based practices. These take into account the wishes of the family, the knowledge of school staff and the needs of the pupil.*	*Develop sustainable and collaborative accredited personal and professional development at various levels for parents and educational practitioners, in both specialist and mainstream, independent and private settings.*
There is not enough personal and professional development available, it is disjointed and there are concerns about the quality of training.	*High quality and coordinated training is available to parents and professionals, with a professional body overseeing this.*	*Bring together specialist providers, independent and private schools, parents and individuals with autism in a collaborative network to enhance greater collaboration between Arabic and English-speaking staff. Task this network with developing collaborative training programs for parents and practitioners that are locally relevant, systematic and coherent.*
There are high levels of knowledge among parent organizations and staff in specialist provisions, and this knowledge could be harnessed to enhance the knowledge, understanding and skills of a great number of therapeutic and educational staff.	*There will be a strong core of autism champions in Qatar who cascade their knowledge to others through a 'train the trainer' approach through engagement in delivering high quality personal and professional development programs.*	*Set up an accreditation system for personal and professional development, with a professional body that oversees it.*
There is lack of awareness among people with disabilities of their rights.	*Individuals with autism and their families are aware of their rights and have access to people who can advocate on their behalf when they need it.*	*Set up an advocacy service staffed with people who have expertise in the rights and needs of individuals on the autism spectrum and their families. Involve autistic individuals and families in this.*
Most materials and resources to diagnose, assess, and teach are developed in English speaking countries.	*There is a wealth of resources and tools that are locally produced and that are linguistically and culturally relevant, reflecting the diversity of the population in Qatar.*	*Ministries of Public Health, and Education and Higher Education gather highly qualified bilingual professionals and parents to coordinate efforts to develop culturally appropriate diagnostic and assessment instruments as well as training materials and information for parents.*
There is not enough specialist staff with knowledge of AESN or autism.	*The current Bachelor and Masters programs in special educational needs at Qatar University are developed to include autism modules, with provision extended to both the Qatari and expatriate population.*	*Work with current providers to develop in-depth University-based provision further. Extend resources and staffing to market this to a wider population and increase recruitment.*
There is a need for further research that is homegrown, local and culturally appropriate.	*Qatar has a strong interdisciplinary research center that researches foundations for evidence-based practice in education.*	*Establish an interdisciplinary international research center for excellence in autism education that integrates efforts from Gulf countries, the wider Arab world and internationally.*

Table 12: Findings, future vision and recommendations emerging from the personal and professional development theme.

5.4. Conclusion

There is enormous potential to transform autism education in Qatar because the country has a strong community of specialists with excellent knowledge and expertise, coupled with support from the Ruling Family and government. Given that there is a thirst for knowledge and a desire to share information among the community of parents and practitioners, we suggest that there is tremendous potential for bringing the expertise of Qataris and expatriates together in a more formalized and strategic way so that all can learn from one another. Harnessing the knowledge base of this community through a strategic approach that focuses on collaborative development of information resources, training materials, frameworks and national standards, could make a major difference to the lives of pupils with autism. People are Qatar's strongest resource and efforts should be made to maximize their expertise so knowledge and understanding can be cascaded to others in need.

Chapter 6

Relevant Websites

The Autism Education Trust

The AET is a partnership in the UK of a wide range of individuals and organizations focused on improving the education of children and young people with autism from the voluntary, public and private sectors. It also actively engages with young people, parents/carers and practitioners to inform its work.

www.autismeducationtrust.org.uk

The cooperative research center for living with autism (Autism CRC)

This center, based in Queensland, Australia, represents collaborations between industry, the community and researchers and it focuses on autism across the lifespan. It actively engages with individuals with autism, and their families in its work.

www.autismcrc.com.au

Action for Autism, India & National Center for Autism, India

This center is a pioneering autism advocacy organization, with their services orchestrated from the National Centre for Autism.

www.autism-india.org

Ohio Center for Autism and Low Incidence

This center is a pioneering center offering a range of services and facilitating the National Autism Leadership Collaborative.

www.ocali.org

Glossary

Additional Educational Support Needs (AESN): A term to describe the needs of a child who has a disability or difficulty that makes learning harder for them than for other children of their age.

Aetiology : Cause/s of a condition.

Applied Behavioural Analysis (ABA): A systematic process of observing a person's behaviour, deciding what needs to be changed and implementing methods to change behaviours.

Attention Deficit Hyperactivity Disorder (ADHD): A condition involving problems with sustained attention, impulsivity and hyperactivity.

Autism Spectrum Disorder (ASD): A term used to indicate that autism comprises a broad range of conditions.

Clicker 5: Multimedia software that supports communication and literacy development (developed by Crick Software).

Co-teaching: Two teachers work in partnership to teach a group of students, with the aim of meeting the differing learning needs of all the students.

Convention on the Rights of Persons with Disabilities (CRPD): An international treaty, adopted in 2006 by the United Nations that recognizes the rights of people with disabilities.

Early Intensive Behavioral Intervention (EIBI): Programs of intensive intervention with pre-school children where desired behaviors are reinforced and unwanted behaviors are discouraged.

Electroencephalogram (EEG): A method of monitoring and recording electrical activity in the brain.

Education for All (EFA): A movement supported by UNESCO with a global commitment to provide good education for all children, youths and adults.

Early Start Denver Model (ESDM): A behavioral early intervention for children with autism aged 12 -24 months.

MMR vaccine: An immunization vaccine against measles, mumps and rubella.

Occupational Therapists: Occupational therapists are trained health professionals who support people to carry out everyday activities that are good for health and wellbeing.

Picture Exchange Communication System (PECS): A method using pictures to teach non-verbal children and adults to communicate and make choices.

Portage: A home-visiting educational service for children with special

educational needs and disabilities, and their families.

'Refrigerator mother': This term was coined in the 1940s to represent the belief that a lack of warmth from mothers caused their child's autism. This theory is now widely discredited.

Response to Intervention (RTI): A multi-tiered approach to the early identification and support of students with learning and behavior needs.

SCERTS® Model: An educational model for enhancing core abilities in Social Communication and Emotion Regulatoin and implementing Transactional Supports for children and young people with autism and their families.

Speech and Language Therapy (SLT): Therapy that helps an individual to increase their communication skills.

Snoezelen room: A controlled multisensory environment that can be soothing, stimulating and therapeutic for people with autism and other conditions.

Treatment and Education of Autistic and Communication Handicapped Children (TEACCH): An approach based on understanding patterns of behavior and thinking in individuals with autism with the aim of preparing them to live and work more effectively at school, at home and in the community.

Visual, Auditory and Kinesthetic (VAK): A multi-sensory approach to teaching and learning

World Autism Awareness (Acceptance) Day (WAAD): : An annual internationally recognized day on April 2nd when people encourage awareness (and acceptance) of autism, adopted by the United Nations in 2007.

Appendices

Appendix One: Focus Group Schedules

Focus Group Schedule (parents)

Topic	Main question	Probes
The participants	*Can you each introduce yourself and say a little about:* *i. your role,* *ii. how long you have been involved in the field of autism,* *iii. how you feel about your work?*	
Current practice	*What approaches and interventions are there for children with autism in Qatar?*	• *Is there agreement in this group about best practice?* • *Why do you think this /these approach (es) is /are best?* • *How do children access provision?* • *How do you feel about current practice?* • *Educational / medical interventions*
Knowledge and understanding	*What is your understanding of what autism is and how would you describe it to someone who didn't know about autism?*	• *Is there agreement?* • *Curable?* • *A broad spectrum?* • *A disability?* • *Are there abilities / strengths in autism?* • *Is there sharing of knowledge about autism between different professional groups?*
Training	*What training is available for people to learn about working with autistic children?* (**Trainers FG:** Give more priority to this question and ask for clarity about the training they give)	• *Training providers?* • *Level and duration?* • *Your opinion about the training?* • *Anything for parents?* • *Are mainstream teachers trained?*
Experience of families	*What do you think it is like for a family with an autistic child in Qatar?*	• *Stigma?* • *Support?* • *Are things changing?* • *Religious dimension?* • *Are parents included as partners?*
Diagnosis	*Is there an effective process for identifying and diagnosing children with autism and how is this done?*	• *How is autism identified?* • *Who diagnoses?* • *What age?* • *Is diagnosis widely available?*
Inclusion	*To what extent do you feel that children with autism are included in education and included in Qatari society?*	• *What is inclusion?* • *Do you think (more) autistic children could go to mainstream schools?*
Outcomes	*From your experience, what are the opportunities for autistic children when they leave school?*	• *College? Work? Centers?* • *What would be good outcomes for an individual with autism?*
Overview	*What do you think are the most important developments that have taken place in Qatar in relation to provision for children with autism?*	• *What pleases you most?*
Recommendations	*What recommendations would you make in relation to policy affecting children with autism?* *What are your recommendations in relation to practice?*	• *Remind them of issues they raised earlier, if appropriate.*

Focus Group Schedule (specialist providers and trainers)

Topic	Main question	Probes
The participants	*Can you each introduce yourself and say a little about:* *i. your role,* *ii. how long you have been involved in the field of autism,* *iii. how you feel about your work?*	
Current practice	*What approaches and interventions are there for children with autism in Qatar?*	• *Is there agreement in this group about best practice?* • *Why do you think this /these approach (es) is /are best?* • *How do children access provision?* • *How do you feel about current practice?* • *Educational / medical interventions*
Knowledge and understanding	*What is your understanding of what autism is and how would you describe it to someone who didn't know about autism?*	• *Is there agreement?* • *Curable?* • *A broad spectrum?* • *A disability?* • *Are there abilities / strengths in autism?* • *Is there sharing of knowledge about autism between different professional groups?*
Training	*What training is available for people to learn about working with autistic children?* (**Trainers FG:** Give more priority to this question and ask for clarity about the training they give)	• *Training providers?* • *Level and duration?* • *Your opinion about the training?* • *Anything for parents?* • *Are mainstream teachers trained?*
Experience of families	*What do you think it is like for a family with an autistic child in Qatar?*	• *Stigma?* • *Support?* • *Are things changing?* • *Religious dimension?* • *Are parents included as partners?*
Diagnosis	*Is there an effective process for identifying and diagnosing children with autism and how is this done?*	• *How is autism identified?* • *Who diagnoses?* • *What age?* • *Is diagnosis widely available?*
Inclusion	*To what extent do you feel that children with autism are included in education and included in Qatari society?*	• *What is inclusion?* • *Do you think (more) autistic children could go to mainstream schools?*
Outcomes	*From your experience, what are the opportunities for autistic children when they leave school?*	• *College? Work? Centers?* • *What would be good outcomes for an individual with autism?*
Overview	*What do you think are the most important developments that have taken place in Qatar in relation to provision for children with autism?*	• *What pleases you most?*
Recommendations	*What recommendations would you make in relation to policy affecting children with autism?* *What are your recommendations in relation to practice?*	• *Remind them of issues they raised earlier, if appropriate.*

Appendix Two: Semi-structured interview schedules

Semi-structured Interview Schedule (autistic individual)

The interviewee will have been identified by an intermediary, a parent or a professional who knows them well and who will have provided the interviewer with some basic information about the interviewee. The intermediary will also have obtained consent and prepared the individual for the interview, explaining to them what it is about and that it can end whenever they wish.

The interviewer may choose from a range of possible questions and adapt the wording according to their own in-the-field assessment of what is most appropriate for the interviewee and to ensure the interviewee's comfort and well-being during the course of the interview. The interview will start with a few straightforward, closed questions related to the interviewee with the aim of helping them feel at ease.

The interviewee will have the option to talk to an Arabic-speaking interviewer.

Topic	Questions	Probes
The participant	*Please can you tell me your name and your age?* *Tell me about your family* *What are the things you like to do?* *Are there some things you don't like? What are they?* *What are you good at?* *What do you find difficult?* *What is your favorite thing to talk about? Can we talk about that for 5 minutes?*	
Diagnosis	*Do you remember getting a diagnosis of autism* **(check out this information beforehand and the suitability of the question)** *How did you feel about it?* *How do you feel about it now?*	• *How old were you?*
Support and information	*What is autism?* *How well-informed do you feel you are about your autism?* *Where could you find out more about it?* *Do you know any other people with autism?* *Are there any opportunities to get together?*	• *Websites? Organizations? School?*
Social belonging	*Do you belong to any clubs or groups where you meet other people?*	• *Websites perhaps?* • *Would you like more opportunities to make friends?*
Educational Provision	*Did you / do you go to school? [or name of organization]* *What was / is good about school?* *Was there anything that you did not like?* *What can you tell me about the things you did at school?*	• *How did / do you get on with the other people there?*
Transition to adulthood	*What are your hopes for the future?*	
Overview	*What is the best thing about your life now?* *What is the worst thing?*	
Recommendations	*Are there any changes that would make life better for you and for other people with autism?*	
Other	*Do you have any other comments that you would like to make?*	

Semi-structured Interview Schedule (parents)

Topic	Questions	Probes
The participant	*Please can you tell me about your child (with autism)?*	• *Name? Age? Siblings? Likes? Dislikes?*
Diagnosis	*What is his / her diagnosis?* *Can you talk about how it felt when you got the diagnosis?*	• *Can you talk about who made the diagnosis and how this was carried out? (age?)* • *How did friends and family respond?*
Support and information For parents	*Can you talk about the support that you have received, from organizations or individuals, following the diagnosis and how useful this has been?* *Do you belong to a parent group and, if so, what has this meant for you?* *How well-informed do you feel you are about [name's] autism and where are you likely to go for information about autism?* *What key messages do you think you would give to the parent of a child newly diagnosed with autism?*	• *Was there support from the person giving the diagnosis?* • *Websites? Organizations? School?*
Knowledge and understanding	*How well do you think the autism spectrum is understood in Qatar?*	• *Is autism more recognized and understood in recent years?*
Educational Provision	*What education is there for [name] and what are your thoughts and feelings about this?* *In your opinion, what are the most important things that you hope for from [name's] education? [eg. Academic skills, social skills and understanding, self-help skills, self-esteem]* *Does the Centre / School involve parents in thinking about what is best for their child?* *Would you like your child to be included in education alongside non-autistic children? [if this is not the case already]*	• *What about the future?* • *To what extent do you feel that your child's needs are being met?*
Inclusion	*From your own experience, to what extent do you feel that children with autism are included in education and in society in Qatar?* *Has your child ever been bullied?*	• *To what extent do you think children with autism are socially accepted?* • *What can you say about social attitudes towards families where there is an individual with autism?* • *Is this the same for children with other 'special needs'?*
Interventions	*Do you have a preference for any particular types of interventions or approaches [for name]?* *Have you been able to receive any training have you had in interventions or approaches for supporting [name]?*	• *How useful are these particular interventions, in your opinion?* • *What are your views on the training you received?*
Transition to adulthood	*Do you know what kind of provision there might be for [name] as he/she moves into adulthood?*	• *What are your hopes for the future?*
Overview	*What are you most pleased with in terms of the provision for [name]?* *What are you least pleased with?*	
Recommendations	*What changes would you like to see in relation to what is available for [name] and for other children with autism in Qatar?*	• *What are the barriers to achieving the developments you would like to see?*
Other	*Do you have any other comments that you would like to make?*	

Semi-structured Interview Schedule (policy makers)

Topic	Questions	Probes
The participant	*Can you tell me about your role and how it relates to children with autism?*	• *Length of experience?* • *Training / knowledge about autism?*
Knowledge and understanding	*What is your understanding of autism?* *How well do you think the autism spectrum is understood in Qatar?* *How are teachers and schools supported to be able to work with children with AESN (including autism)?* *What opportunities are there for people to learn about autism?* *What opportunities are there for knowledge and practice to be shared between different groups, including professionals, families and community groups?*	• *How would you describe autism?* • *Is autism more recognized in recent years?* • *Do people from different professional groups have the chance to share knowledge?* • *Are parents involved in deciding policy? How?* • *Are there any autistic advocates who are able to advise on policy?*
Indentification / diagnosis	*How are children with autism identified?* *How is the diagnosis carried out?*	
Assessment of needs	*How do practitioners assess the needs of children with autism?*	• *What assessment tools do they use?* • *Is there an understanding that not all children with autism have the same needs?*
Provision	*What educational provision is made for children with autism in Qatar?* *How are families supported?*	
Inclusion	*Is there a policy on inclusion?* *To what extent do you feel that children with autism are included in education?* *And in society?* *What does inclusion mean to you?*	• *Are there differences in the extent of inclusion when there are additional learning needs as well as autism?* • *To what extent do you think children with autism are socially accepted?* • *What can you say about social attitudes towards families where there is an individual with autism?* • *Is this the same for children with other 'special needs'?*
Interventions	*What kind of interventions are used to support children with autism in Qatar?* *Do you have a preference for any particular types of interventions?*	• *How useful are these particular interventions, in your opinion?* • *What are your views on the training that is available for practitioners?*
Transition to adulthood	*Do you know what kind of provision exists for individuals with autism as they move into adulthood?*	• *Can you give any examples?*
Overview of current practice	*Can you describe current access to and quality of provision for autism?* *What are you most pleased with in terms of the provision for autism in Qatar?* *What do you think are the key aspects of good practice for children with autism?*	• *In your setting / other settings* • *What do you see as the main achievements?*
Recommendations	*What changes would you like to see in relation to practice for children with autism in Qatar?* *What changes would you like to see in relation to policy for children with autism in Qatar?* *How might this be achieved?*	• *What are the barriers to achieving the developments you would like to see?*

Semi-structured Interview Schedule (specialist providers)

Topic	Questions	Probes
The participant	*Can you tell me about your role and how it relates to children with autism?*	• *Length of experience?* • *Training?*
The organization	*Can you say how long [name of organization] has been running and how it came into being?* *How is it financed and is the funding secure for the future?* *How many children do you have and what is their range of needs?* *How long do children stay here and where do they progress to when they leave here?*	
Knowledge and understanding	*What is your understanding of autism?* *How well do you think the autism spectrum is understood in Qatar?* *How are teachers and schools supported to be able to work with children with SEN (including autism)?* *What opportunities are there for people to learn about autism?* *What opportunities are there for knowledge and practice to be shared between different groups, including professionals, families and community groups?*	• *How would you describe autism?* • *Is autism more recognized in recent years?*
Indentification / diagnosis	*How are children with autism identified?* *How is the diagnosis carried out?*	
Assessment of needs	*How do practitioners assess the needs of children with autism?*	• *What assessment tools do they use?* • *Is there an understanding that not all children with autism have the same needs?*
Provision	*What educational provision is made for children with autism in Qatar?* *How are families supported?*	
Inclusion	*What does inclusion mean for you?* *To what extent do you feel that children with autism are included in education and in society?*	• *Are there differences in the extent of inclusion when there are additional learning needs as well as autism?* • *To what extent do you think children with autism are socially accepted?* • *What can you say about social attitudes towards families where there is an individual with autism?* • *Is this the same for children with other 'special needs'?*
Interventions	*Do you have a preference for any particular types of interventions?* *What kind of training have you had in interventions?*	• *How useful are these particular interventions, in your opinion?* • *What are your views on the training you received?*
Transition to adulthood	*Do you know what kind of provision exists for individuals with autism as they move into adulthood?*	• *Can you give any examples?*
Overview of current practice	*Can you describe current access to and quality of provision for autism?* *What are you most pleased with in terms of the provision for autism in Qatar?* *What do you think are the key aspects of good practice for children with autism?*	• *In your setting / other settings* • *What do you see as the main achievements?*
Recommendations	*What changes would you like to see in relation to practice for children with autism in Qatar?* *What changes would you like to see in relation to* **policy** *for children with autism in Qatar?* *How might this be achieved?*	• *What are the barriers to achieving the developments you would like to see?*

Semi-structured Interview Schedule (trainers)

Topic	Questions	Probes
The participant	*Can you tell me about your role and how it relates to children with autism?*	• *Length of experience?*
Training given	*Can you tell me about the autism-related training that is on offer here?*	• *Type of training, duration* • *Level and qualifications awarded?* • *Numbers and background of students*
Knowledge and understanding	*What is your understanding of autism?* *How well do you think the autism spectrum is understood in Qatar?* *How are teachers and schools supported to be able to work with children with autism?* *What opportunities are there for knowledge and practice to be shared between different groups, including professionals, families and community groups?*	• *How would you describe autism?* • *Is autism more recognized in recent years?*
Indentification / diagnosis	*How are children with autism identified?* *How is the diagnosis carried out?*	
Assessment of needs	*How do practitioners assess the needs of children with autism?*	• *What assessment tools do they use?* • *Is there an understanding that not all children with autism have the same needs?*
Provision	*What educational provision is made for children with autism in Qatar?*	• *How are families supported?*
Inclusion	*What does inclusion mean for you?* *To what extent do you feel that children with autism are included in education and in society?*	• *Are there differences in the extent of inclusion when there are additional learning needs as well as autism?* • *To what extent do you think children with autism are socially accepted?* • *What can you say about social attitudes towards families where there is an individual with autism?* • *Is this the same for children with other 'special needs'?*
Interventions	*Do you have a preference for any particular types of interventions?* *As a trainer, what kind of training have you received in interventions?*	• *How useful are these particular interventions, in your opinion?* • *What are your views on the training you received?*
Transition to adulthood	*Do you know what kind of provision exists for individuals with autism as they move into adulthood?*	• *Can you give any examples?*
Overview of current practice	*Can you describe current access to and quality training for autism?* *What are you most pleased with in terms of autism-related training in Qatar?*	• *What do you think are the key aspects of good practice for children with autism* • *What do you see as the main achievements?*
Recommendations	*What changes would you like to see in relation to training related to autism?* *What changes would you like to see in relation to* **practice** *for children with autism in Qatar?* *What changes would you like to see in relation to* **policy** *for children with autism in Qatar?* *How might this be achieved?*	• *What are the barriers to achieving the developments you would like to see?*

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Dr Guldberg is Reader in Autism Studies and Director of the Autism Centre for Education and Research, University of Birmingham, UK. She conducts real-world research in the classroom, with a focus on pedagogy, social learning and the specific learning needs of children with autism. She was instrumental in the development of the Autism Education Trust partnership training programs and is Principal Investigator of the 'Transform Autism Education' project which researches good autism educational practice in Greece and Italy by investigating barriers to inclusion, enhancing the knowledge and practice of education staff and promoting good outcomes for individuals on the autism spectrum.

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Ryan Bradley is a Research Fellow in the Autism Centre for Education and Research (ACER) at the University of Birmingham. He is working on the Transform Autism Education research project with partners in Italy and Greece. He is also a doctoral student within ACER and has previously collaborated with them as a core author of the Autism Education Trust's national Schools and Early Years Programs. He is passionate about improving outcomes for autistic children and young people and has a strong interest in researching school based approaches and inclusion.

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About The University of Birmingham

The University of Birmingham is a high-ranking global university that encourages bold and independent thinking, offering students the highest quality academic experience that stretches and challenges them. Birmingham has been challenging new ground for more than a century. Characterized by a tradition of innovation, research at the University has pushed forward the boundaries of knowledge and made an impact on people's lives. The Autism Centre for Education and Research (ACER) is a thriving research center situated within the Disability, Inclusion and Special Needs Department in the School of Education at University of Birmingham. At the time of writing this report, the School of Education is ranked joint sixth in Europe and 25th globally within the QS World University Rankings. Furthermore, the Guardian places the School of Education fourth in the UK in its University Guide. ACER is an international center focusing on research and teaching in education and care for individuals with autism across the lifespan.

About WISE

world innovation summit for education
مؤتمر القمة العالمي للابتكار في التعليم

An Initiative of Qatar Foundation

The World Innovation Summit for Education was established by Qatar Foundation in 2009 under the leadership of its Chairperson, Her Highness Sheikha Moza bint Nasser. WISE is an international, multi-sectoral platform for creative, evidence-based thinking, debate, and purposeful action toward building the future of education. Through the biennial summit, collaborative research and a range of on-going programs, WISE is a global reference in new approaches to education.

The WISE Research series, produced in collaboration with experts from around the world, addresses key education issues that are globally relevant and reflect the priorities of the Qatar National Research Strategy. Presenting the latest knowledge, these comprehensive reports examine a range of education challenges faced in diverse contexts around the globe, offering action-oriented recommendations and policy guidance for all education stakeholders. Past WISE Research publications have addressed issues of access, quality, financing, teacher training, school systems leadership, education in conflict areas, entrepreneurship, early-childhood education, and twenty-first century skills.

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