

**EDUCATIONAL INCLUSION FOR CHILDREN WITH AUTISM IN PALESTINE.**

**What opportunities can be found to develop inclusive educational practice and provision for children with autism in Palestine; with special reference to the developing practice in two educational settings?**

**by**

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### **Amendments to names used in thesis**

The Amira Basma Centre is now known as **Jerusalem Princess Basma Centre**  
Friends Girls School is now known as **Ramallah Friends Lower School**

## **ABSTRACT**

This study investigates inclusive educational understandings, provision and practice for children with autism in Palestine, using a qualitative, case study approach and a dimension of action research together with participants from two educational settings. In addition, data about the wider context was obtained through interviews, visits, observations and focus group discussions. Despite the extraordinarily difficult context, education was found to be highly valued and Palestinian educators, parents and decision-makers had achieved impressive progress. The research found that autism is an emerging field of interest with a widespread desire for better understanding. However, autism was not generally well understood or reliably identified and there was a lack of opportunity for sharing knowledge and practice. Autism was often perceived in terms of deficits, and the breadth, diversity and abilities within the autistic population were not well understood. Although there was general support for the official policy of inclusive education, autistic children were sometimes stigmatised, isolated and excluded. Notwithstanding many challenges, there were examples of dedicated but insecurely funded non-government provision, indicating that Palestinians have much to contribute to the international discourse on the inclusive education of autistic children. The action research dimension of the study identified features of successfully developing good educational practice for pupils with autism within two settings and considered the viability of replicating these more widely within Palestine. Concluding recommendations call for development of knowledge and practice in Palestine, drawing on, but not dictated by, the international pool of knowledge on inclusive autism practice. The study highlights a need for better identification of autism; for building capacity for contextually-appropriate inclusive educational provision; and for reconceptualising inclusion as a process of enabling participation in education. It proposes that there is a need for collaboration between professionals, parents and people with autism to share knowledge and practice, and suggests that this could be achieved through a Communities of Practice approach, building on current local collaborations between schools, organisations and communities.

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## **DEDICATION**

This thesis is dedicated to children with autism in Palestine, their families and allies.

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## Abbreviations

AAC	Augmentative and alternative communication
ABA	Applied Behavioural Analysis
ABC	Princess Basma Centre
ACER	Autism Centre for Education and Research, University of Birmingham, UK
ADHD	Attention deficit hyperactivity disorder
ACI	An-Najah Child Institute
AET	Autism Education Trust
ASD	Autism spectrum disorder
BAT	Basha Behavioural Autism Spectrum Disorders Screening Test
BBC	British Broadcasting Corporation
BDS	Boycott Divestments and Sanctions
CBR	Community-based Rehabilitation
CoP	Communities of Practice
CRC	Convention on the Rights of the Child
CSIE	Centre for Studies on Inclusive Education
DfES	Department for education and skills (UK)
DIR	Developmental, individual difference, relationship-based
DSM-V	Diagnostic and Statistical Manual version 5
EU	European Union
FACS	Friends of Autistic Children Society
FGS	Friends Girls School
FBS	Friends Boys School
FN	Field Notes
IB	International Baccalaureate
ICD-10	International Classification of Diseases - 10
ICT	Information and communications technology
IE	Inclusive Education
IEC	Inclusive Education Counsellor
INSET	In service education and training
IPA	Interpretative Phenomenological Analysis
IPAA	Inclusive pedagogical approach in action
JACCO	Jerusalem Autistic Child Care Organisation
JEA	Jerusalem Education Authority
MENA	Middle East and Africa
MOEHE	Ministry of Education and Higher Education
MRC	Medical Research Council (UK)
NAD	Norwegian Association for the Disabled
NGO	Non-governmental organisations
NIASA	National Initiative for Autism: Screening and Assessment (UK)
NICE	National Institute for Health and Clinical Excellence (UK)
NT	Neurotypical
OfSTED	Office for standards in education (UK)
OPT	Occupied Palestinian Territories
PA	Palestinian Authority
PACBI	Palestinian Campaign for the Academic and Cultural Boycott of Israel
PASSIA	Palestinian Academic Society for the study of International Affairs.
PCBS	Palestinian Central Bureau of Statistics
PD	Physical disability
PDD-NOS	Pervasive developmental disorder not otherwise specified
PECS	Picture Exchange Communication System
PYP	Primary Years Programme
QCERD	Qattan Centre for Educational Research and Development
SCERTS	Social Communication, Emotional Resilience and Transactional Support
SEN	Special educational needs
TdH	Terre-des-Hommes Inclusion Project
TEACCH	Treatment and Education of Autistic and Related Communication Handicapped Children
UBD	Understanding by Design
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations International Children's Emergency Fund
UNRWA	United Nations Relief and Works Agency for Palestine
UoB	University of Birmingham
WAFA	(Palestinian national information centre)
WAQF	(Islamic charitable trust)
WHO	World Health Organisation

## **CHAPTER 1: INTRODUCTION TO THE THESIS**

### **1.1 How the research came about**

This research grew from the convergence of three interests: autism, Palestine and inclusion. As a teacher and as an advisory teacher for children on the autism spectrum I was increasingly fascinated by autism and the way it needed teachers to be responsive, counter-intuitive and informed. Since 2004 I had also been visiting Palestine annually, hosted by The Qattan Centre for Educational Research and Development (QCERD), offering workshops in 'special needs' for teachers. My offers to teach about autism had fallen on deaf ears to begin with as autism was not perceived as a relevant issue, but in 2010 I led a workshop about autism for a group of early childhood teachers on QCERD's Diploma course in Ramallah. It was well-received and discussions during and after the workshop pointed to a desire for knowledge about autism in Palestine. A senior researcher at QCERD asked if I would develop this work and, accepting the challenge, I sought the support of the Autism Centre for Education and Research (ACER) at the University of Birmingham (UoB) to ensure rigour in my work. Initially I enrolled for an MPhil study but as I amassed more and more data it seemed appropriate to transfer to PhD level. It became clearer to me during my research journey that my study was also about inclusion. I had long held an intuitive belief in inclusion and my study encouraged me to probe my understanding of inclusion, both in relation to autism and in relation to Palestine. My motivation was to do something useful for Palestine's teachers in response to many warm welcomes there, a growing sense of comradeship, and the admiration I felt for the resilience of Palestinians in the face of oppression. Once embarked on the research my sense of commitment was quickly extended to others - parents, autistic

children, practitioners, members of the community and decision makers. I chose a broad focus for my research, making it essential to keep a clear sight of my questions (Figure 1, below).

## **1.2 Relevance and timeliness**

Worldwide there is a growing increase in identification of autism. Estimates range from one in a hundred (Baird et al., 2006) to one in sixty eight (Centre for Disease Control and Prevention, 2014) and evidence from the literature does not indicate that Palestine is likely to be any different (Ben-Sasson, 2012; Daley, 2002; Elsabbagh, 2012). This suggests that all teachers in inclusive settings are likely to come across children with autism, and as Palestine's education strategists aim for inclusion, teachers there need to know about autism. The complex nature of autism highlights a need for training and knowledge sharing so that the needs of autistic children can be understood. However, I needed to ask myself whether this was really an issue of importance for Palestinians or were they being asked to problematise an issue about people who are just a bit atypical? Did anything need to change and did my research risk importing western ideas of disability or diversity which was not useful in the Palestinian culture? As Grinker (2009) put it: 'Autism .... does not exist outside of culture. It is culture that sees something as abnormal or wrong, names it and does something about it' (p14). Did Palestinians want to see autism, name it and do something about it? Did they not have more important issues as they struggled against injustice, oppression and deprivation with precious and limited resources? These were some of the questions I had in mind as I, perhaps audaciously, pursued my research in a culture that is not my own. Answers to these questions are contained in my findings and offer confirmation that good practice in relation to

educational inclusion for autistic children is indeed an issue that is important to Palestine at this time and there is an international body of knowledge that can be shared with Palestine and to which they can contribute.

Inclusion is an issue that Palestine has been grappling with since signing the Salamanca agreement (UNESCO,1994) and my thesis is relevant to debate about inclusion in Palestine. Developments towards inclusion of children with diverse needs such as autism come hand-in-hand with the need to examine the educational environment and the way we teach and my thesis proposes that this is pertinent to the current debate in Palestine about pedagogy (Al-Ramahi & Davies, 2002; Farrell, 2007; Karlsson, 2004; Khaldi & Wahbeh, 2002; UNESCO, 2011; UNICEF, 2011; Wahbeh, 2011; Van Dyke & Randall, 2002). I believe my research makes a timely and relevant contribution not only to the development of good autism practice in Palestine but also to the struggle for educational inclusion of children with additional needs. My research also seeks to be inclusive of a multiplicity of voices and asks: what can we learn from the Palestinian experience and how can Palestinians contribute to the international discourse on the educational inclusion of children with autism?

### **1.3 The support of the Qattan Centre for Educational Research and Development**

My research was made possible by the support of QCERD, an independent Palestinian research institution. QCERD's primary mission is to assist Palestinian teachers in acquiring new skills and improving their knowledge. The Centre perceives its role as complementary to the work of official and unofficial institutions such as the Ministry of Education, non-governmental organisations and universities which are actively involved in planning and providing educational services. QCERD provided



me with financial and practical support as well as advice, guidance, encouragement and a bridge to local teachers, organisations and those who were interested in my study. Their financial support funded travel to and from Palestine for five field visits (Table 8) plus a sixth visit for a final Study Day, as well as accommodation and travel costs whilst in Palestine. Their support included the invaluable provision of a Research Assistant, Rasha Mesleh, to help with translation and coordination of research activities and I had access to QCERD's well-resourced facilities in Ramallah and the support of their expert IT team. I am truly indebted to QCERD for their invaluable support. QCERD left me free to make my own decisions about the research design.

#### **1.4 Research design**

My reading on research methodology led me to opt for a qualitative, interpretivist approach as I wished to go beyond my own beliefs and values to try to understand Palestinian perspectives in relation to my research question. I was particularly sensitive to this as I started out on my research journey, aware of the dubious legacy of British involvement in Palestine and mindful of the dangers of cultural hegemony. The literature warns against the inappropriate introduction of approaches into cultures where they do not fit with local needs (Kisjani, 1998; Miles, 2002; Thomas, 2013b). In relation to autism there is a rich international body of evidence-based practice and expertise to draw on but there is also a need to consider transferability to other regions of the world, such as Palestine. It was the cross-cultural challenges of my study that confirmed my choice of an interpretivist paradigm and this in turn led to the need for the design of my study to emerge rather than be prescribed.

The research followed two broad strands (Figure 1 below). The first strand, a 'contextual enquiry', sought data about the current situation relating to children with autism in Palestine through a series of interviews and visits involving a range of people and places. The second strand used a case study approach with a dimension of action research involving two educational settings: Friends School in Ramallah and Amira Basma Centre in East Jerusalem. Both were working to include children with autism and had expressed a wish to work with me. At the outset my main focus was on the case study strand, but the contextual enquiry grew to equal significance as the research progressed and rich opportunities for data-gathering opened up. For instance, the Ministry of Education became interested in my study and requested workshops for their staff, giving me unforeseen access to perspectives that were germane to my research. Throughout the study I used a range of data-collection methods including semi-structured interviews, questionnaires, observation and focus group discussions.

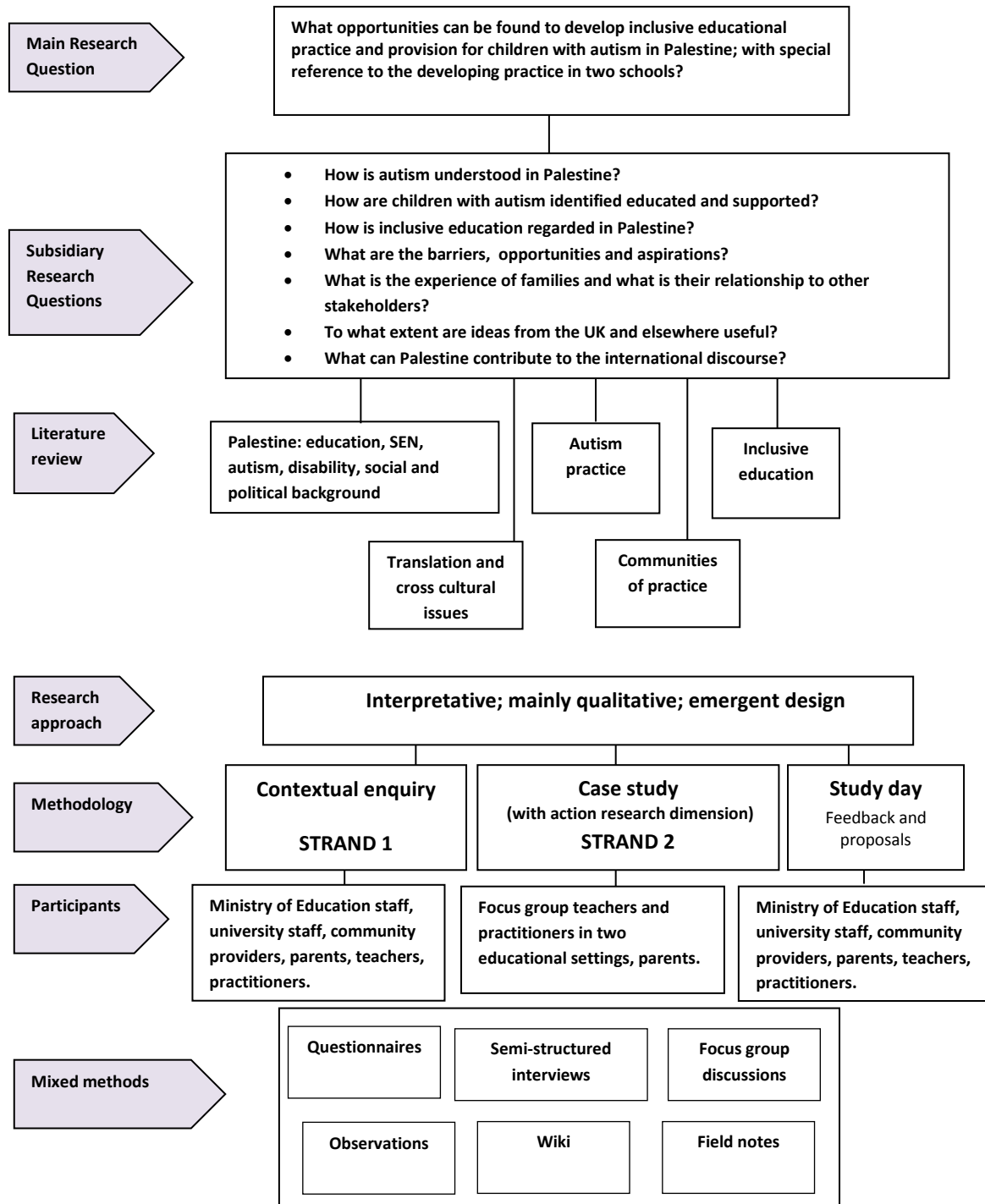


Figure 1: Design Frame

## **1.5 Theoretical underpinning**

My reading and experience gave me some of the theoretical understandings that sit at the heart of my study, underpinning the process of the research and the writing of my thesis. Firstly, the social model of disability sees a person with autism not as defective, faulty and in need of fixing, but as legitimately different. Although society may present difficulties for the autistic person, the difficulties do not reside in the person, as a medical model of disability would have us believe, but in the barriers to participation that society creates, and so it follows that society holds a responsibility for removing those barriers. Schools are complex social institutions and a social model of disability requires that educators dismantle barriers, adopt inclusive attitudes and create environments that allow the child to participate (Slee, 2000; Thomas & Loxley, 2001). This is an issue of relevance in Palestine where my study indicates a prevalence of the medical and charitable models of disability. My study suggests that this is perhaps a fundamental barrier at the heart of Palestine's struggle to come to terms with inclusion despite an expressed wish to do so, and that a better understanding of these different approaches to disability enables us to explore important differences between inclusion and integration.

Another theoretical cornerstone of my study is based on Communities of Practice (CoP) (Wenger, 2009). CoPs are groups of people who collaborate to harness and develop knowledge and practice within a shared domain of human endeavour. The CoP model, discussed on pages 78-82, became important to me as a way of thinking about the nub of my main research question: how can Palestine develop inclusive approaches for children with autism? The CoP model became useful for sharing of knowledge and practice within and across professional and community boundaries.

Moreover, it chimed with the participatory aspect of my research design whereby I sought to share knowledge and practice within and between the two participating educational setting in my case study and explore the means of doing this. I was influenced by Wahbeh (2011), a Palestinian educational researcher, who had identified the potential of CoP as a model for professional development and empowerment within the teaching profession.

## **1.6 Terminology**

Debates about whether to use 'autism spectrum condition' or 'autism spectrum disorder' (Jordan, 2007; Jones et al., 2008) balance the need to accept difference with the need to provide a useful 'label'. It is now common in the literature to refer to 'autism' or 'autism spectrum' without 'disorder' or 'condition' (Jones et al., 2008) and the terminology in my thesis follows this trend. 'Disorder' and 'disability' to describe autism are at odds with a growing tendency to see autism as a difference rather than a disability and to recognise its strengths (Motttron, 2011; Stanton, 2013). There is also debate about the use of the word 'special' as in 'special needs'. Rather than seeing 'special' as a positive word to describe people with additional needs, an online survey (Ouch blog, 2003) found it to be the fifth most offensive word related to disability. In my thesis I have often needed to use the terms 'disability', 'disorder' and 'special needs' as these are the terms others have used and I wanted to refer to people in the terms that they themselves would prefer. However, there is no consensus on this. Widely accepted person-first language (eg. 'child with autism') is often thought to be more respectful, but this is now less acceptable for some within the autistic community who argue for condition-first language (eg. 'autistic child'). Jim Sinclair (1999) and Clare Sainsbury (2000) see autism as an essential part of who

they are and feel that person first language implies that autism is something bad and so prefer to be called autistic persons. In my thesis I use both person-first and condition-first terminology.

A far more taxing issue related to terminology has been the need for translation in all aspects of my study: preparation of research instruments, interpretation of data, making presentations, developing materials. The significance of this issue increased during the course of my study, as I was jolted into a growing awareness of the hazard of mis-translation. My thesis discusses the struggle for semantic and conceptual equivalence across two languages, especially challenging where the research topic is one whose language is nuanced, changing and contentious.

## **1.7 Organisation of the thesis**

This thesis is presented in nine chapters. This first chapter is followed by three chapters that review the literature. Chapter two explores the literature relating to the context of my study, Palestine, and gives an overview of the social, political and historical background to the present situation there and the impact of the occupation. It considers education in Palestine, contextualised within the political challenges, to see what has been achieved in difficult circumstances and explores literature relating to disability, 'special needs' and autism in Palestine. My reading has been confined to literature that is available in English. Chapter three explores the discourse on inclusion, the arguments of its advocates, the barriers and its relationship to special educational needs (SEN). A distinction is drawn between inclusion and integration. I describe inclusion as a process and consider the importance of knowledge and practice, leading to a model for the sharing and harnessing of knowledge and practice, based on ideas drawn from the literature on communities of practice

(Wenger et al., 2002; Wenger, 2009; Guldberg et al., 2013). Chapter 4 looks at literature relating to autism and international notions of practice in education of children with autism and considers what inclusion might mean for autistic children in Palestine. Following on from my three literature review chapters, Chapter 5 describes the research design and presents the research questions. It explains the two strands of the methodology: a contextual enquiry that explored autism practice and provision within Palestine; and a paired case study with a dimension of action research where I worked with participants in two settings.

Research findings, organised within 4 data sets, are analysed and presented within the next three chapters. Chapter 6 explores findings from the contextual enquiry. Data here are presented within two sets: data set one, the broad context, draws on interviews and observations made during visits; and data set two is drawn from a workshop that I ran for the Ministry of Education and Higher Education (MOEHE). Chapter 7 presents the findings from the case study (data set 3). These two chapters (6 and 7) represent the primary data and I discuss and triangulate my findings as I proceed, giving a synthesis of the findings at the end of each chapter. Chapter 8 (data set 4) is a smaller adjunct from a Final Study day that was held at the end of my research to present my findings for research participants and others. The relationship between the data sets is shown in Figure 14 (p.111). After this comes my final analysis in Chapter 9.

In addition to the appendices at the end of the thesis, further data is submitted on a CD and this is referred to in the text with the prefix 'CD' (eg, CD:F4). They are listed in Appendix 15.

## 1.8 Introduction to the following three chapters

Three main areas of reading for my research are explored in the following chapters: Chapter 2, the Palestinian context; Chapter 3, educational inclusion; and Chapter 4, autism education. Figure 2 shows how these three areas intersect and it is the overlap between them that is of particular interest for my research. Within these intersections cross cultural perspectives become significant and demand probing questions for my study.

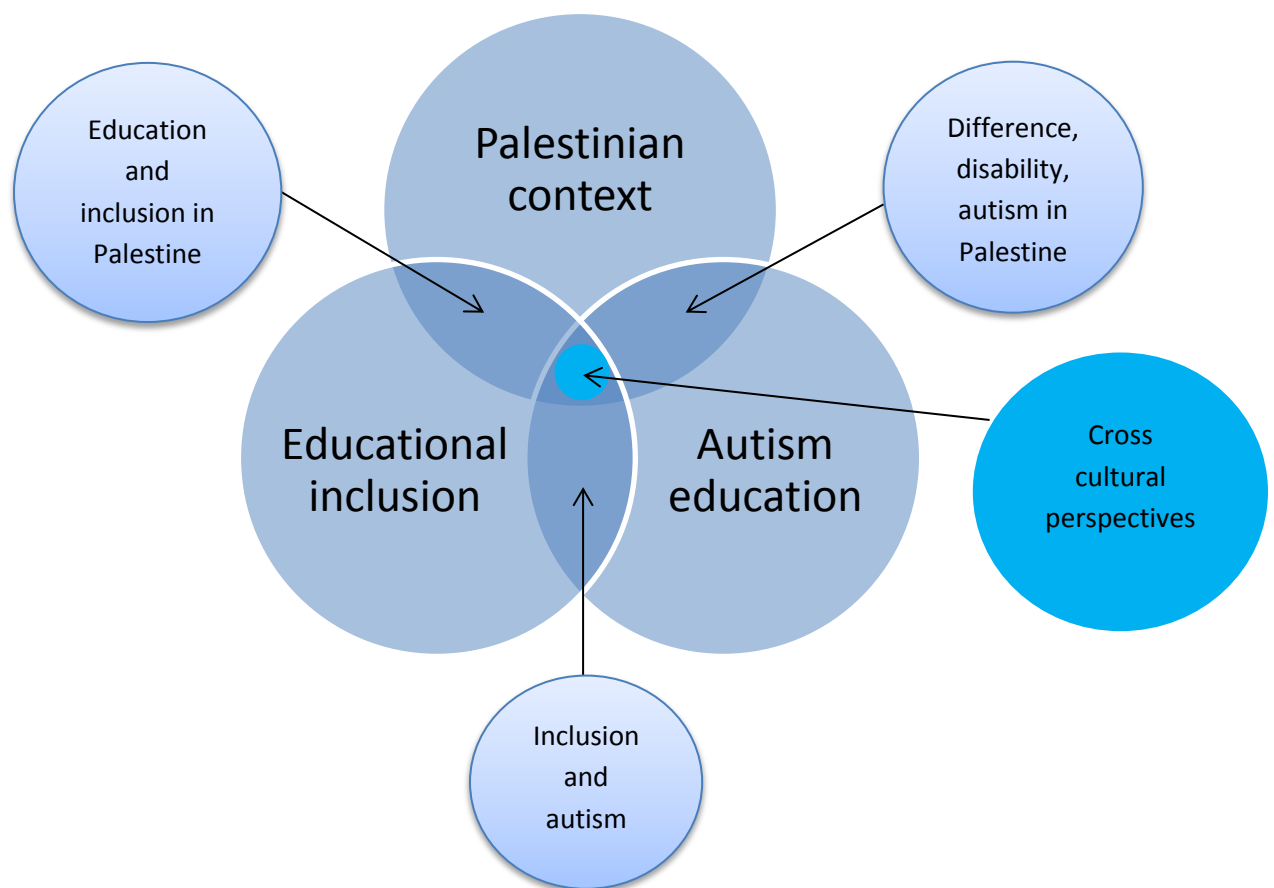


Figure 2: The overlapping areas within my review of the literature



I have dealt with the overlap between the three chapters by making, hopefully logical, choices about which discussions belong where, and signposting when an issue arises again elsewhere.

## **CHAPTER 2: THE CONTEXT: PALESTINE: A REVIEW OF THE LITERATURE**

### **2.1 Introduction**

Any study relating to developments in Palestine must be looked at against the backdrop of forty seven years of Israeli occupation that has led to stagnation and geographical fragmentation for Palestine. In this chapter I draw on international and Palestinian writings to describe the historical, geographical and political landscape of Palestine today, before looking at education, disability and special needs in Palestine. A look at the wider political landscape is necessary not only for an understanding of developments in Palestine but also as a lens through which to comprehend the thinking and perceptions of participants in my research. In addition, this chapter illuminates research decisions that were affected by the challenging conditions of life in Palestine. Any account of Palestine's history treads on contentious ground and, taking a lead from the late Palestinian exile, intellectual and polymath, Edward Said (1979) I do not give a 'both sides' approach. Rather, I position myself as supportive of the right of Palestinians to self-determination and freedom from oppression.

### **2.2 The Nakbah**

The history of modern Palestine is encapsulated in the maps below (Figure 3) which illustrate the Palestinian loss of land and fragmentation between 1948 and 2000, a process continuing today. Following the 1948 war, known by Palestinians as the Nakbah (the catastrophe) and the creation of Israel, most of the land was lost that historically belonged to Palestine and as the maps illustrate, only a tiny percentage remains, with communities broken apart in the fragmented Palestinian territories of

the West Bank and Gaza. This remaining land is increasingly being absorbed into Israel.

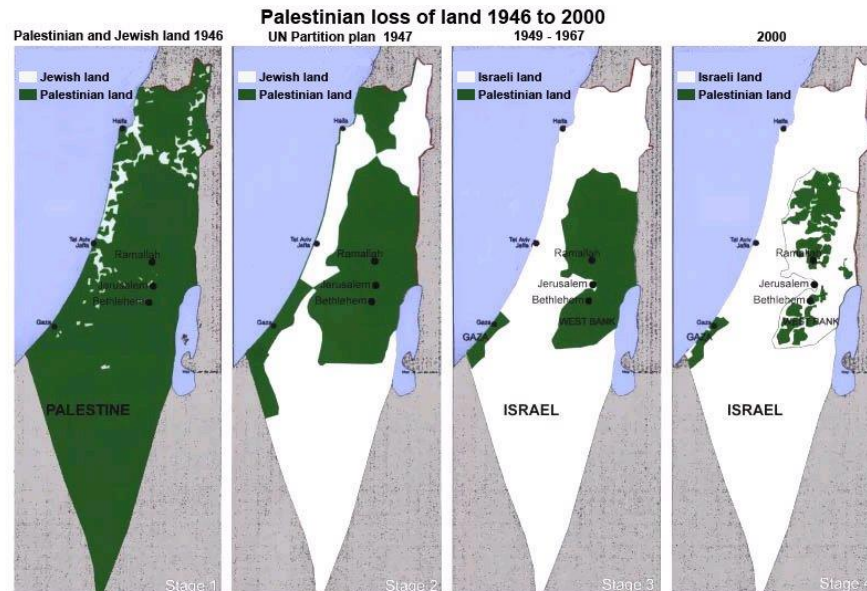


Figure 3: Palestinian loss of land

Four centuries of Ottoman rule in the vast Middle Eastern region that had included Palestine was followed by the imposition of the British Mandate whereby Britain ruled over Palestine from 1920 until the state of Israel was declared in 1948. This resulted in tens of thousands of displaced Palestinian Arabs losing homes, villages, land and lives. Jewish immigrants from Europe settled on land that had been inhabited by Palestinians. An ensuing war between Israel and Arab states led to Israeli appropriation of 78% of the land that previously belonged to Palestine, an event known to Israelis as ‘the war of Independence’ but to Palestinians as the Nakbah<sup>1</sup>. Dr Ilan Pappé, in his scholarly historical study (Pappé, 2006a) has convincingly described these events as the ‘ethnic cleansing of Palestine’. Later, in 1967 the Six-Day War resulted in Israeli military occupation of the West Bank and Gaza, a

<sup>1</sup> The Nakbah, or ‘catastrophe’ refers to events in 1948 when 700,000 Palestinians fled or were driven out from their homes.

situation that has continued until now. The First Intifada<sup>2</sup>, 1987-1993, in which it is estimated that 10,000 young people, mainly boys, became physically disabled, ended with the Oslo Accords of 1993, giving the Palestinian Authority not autonomy but some responsibility for the occupied territories. Parliamentary elections were held in 1996. A second Intifada, known as the Al Aqsa Intifada, started in 2000 as a result of military aggression and the failure of a meaningful peace process, and the subsequent four years were characterised by military incursions, restrictions on travel and obstacles to daily life, such as school closures. The construction of the separation wall in the West Bank, 'contrary to international law' (International Court of Justice, 2004), as well as the appropriation of yet more Palestinian land, divided and isolated communities so that internal travel became difficult. Israeli settlements, now appropriating 42.8% of Palestinian land (PASSIA, 2011) are illegal under international law and continue to grow in size and number with roads, which Palestinians are not permitted to use, linking them to Israel and each other, sometimes cutting Palestinian villages in two. The West Bank has been, essentially, divided up into Bantustans<sup>3</sup> (Pappe, 2006) making the job of the Palestinian Authority difficult in terms of the management of its functions. As well as geographical disconnection within the West Bank, the occupied territories are even more harshly severed into two separate regions, the West Bank and Gaza, and travel between them is almost impossible for Palestinians. Following electoral successes of Hamas in 2006, there was an international boycott of the Palestinian Authority. Internal political crisis ensued and the rift between Hamas and Fatah led to the seizure of

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<sup>2</sup> Intifada = Palestinian uprising

<sup>3</sup> Bantustans: unconnected enclaves with limited self-governance as in apartheid South Africa (Howell 2007)

control of Gaza by Hamas, so that the fragmentation between the West Bank and Gaza became political as well as geographical.

The West Bank of Palestine is inhabited by 2.7 million people and 1.8 million live in Gaza (Wikipedia, 2014). In addition, 1.6 million Palestinians live in Israel. In the West Bank 80-85% are Muslim (mainly Sunni); 1-2% are Christian; 12-14% are Jewish settlers; the population of Gaza is predominantly Muslim. The Palestinian diaspora is much larger with an estimated figure for 2005 of 10.1 million Palestinians worldwide (Palestine Central Bureau of Statistics, 2006). Palestinian society is complex and contradictory. Ramallah, where I am based when I visit Palestine, is a modern, forward-looking centre of commerce and administration with a diverse population. However, most of its inhabitants are not permitted to make the six mile journey to Jerusalem, the disputed capital of both Palestine and Israel. Even those who have permits to travel have long waits at checkpoints which are humiliatingly reminiscent of cattle herding facilities (Figure 4). This is just one of the indignities which are a feature of everyday life.



Figure 4: Qalandia checkpoint between Ramallah and Jerusalem

Forty four years of Israeli occupation have left their mark, not only on the physical infrastructure of towns and villages but also on society, transport systems, institutions, refuse disposal, the geography and, of course, education. Mourid Barghouti (2004) wrote, 'The occupation has forced us to remain with the old: that is its crime' (p. 69), but as I found, there are many progressive, dynamic people in Palestine whose form of resistance to the occupation is to build a strong forward-looking society, and one of the ways to do this is through education.

### **2.3 The Occupation**

'There is no humane way to rule people against their will'. Naomi Klein (2007:126)

Palestine is occupied, some prefer to say 'colonised' (Cook, 2014; Pappe, 2014), by Israel and this has a profound impact on the lives of Palestinians. International and Palestinian voices combine to tell us of the experience living in an occupied country: the daily and commonplace brutality and oppression (Baroud, 2013; Chomsky, 2014; Chomsky, 2010; Nabulsi, 2014; Pappe, 2006a; Pappe, 2006b ); the long history of 'ethnic cleansing' that has robbed Palestinians of most of their homeland (Pappe, 2006a); the suffering of Palestinian children (CAAC, 2010; Pilger, 1991); the lack of freedom of movement within the occupied territories and beyond (Barghoutti, 2004; Fleishman, 2014; Howell, 2007; Tutu, 2014); the repeated flouting of international law by the Israelis (Corbyn, 2014; Hunter, 2014; Pappe, 2010 and 2006; Pilger, 2002; Said, 1979; Tutu, 2014); the economic benefits for the Israelis of violence and oppression rather than peace (Klein, 2007); and the by-and-large international disregard for the suffering of Palestinians (Milne, 2014; Said, 1979). Inhumane treatment of the Palestinians is made possible because Israeli soldiers (most Israelis

serve time in the army) are trained not to see Palestinians as human beings but as potential terrorists (Independent, 2014). The word 'occupation' to describe the situation in Palestine is perhaps too mild. Cook (2014) argues that the word "occupation" is inadequate as it implies a temporary state of affairs before normality is restored and that this is the opposite of what is happening in Jerusalem, the West Bank and Gaza, where 'the occupation is entrenching, morphing and metastasizing'. Ilan Pappé (2014), more accurately, talks of 'colonisation' rather than 'occupation' to describe the situation. The stark fact of 230 illegal settlements housing 500,000 Israeli settlers in the West Bank and East Jerusalem (Palestine Solidarity Campaign, 2009), settlements that then control natural water sources so that Palestinians are left in water poverty (Friends of Al-Aqsa, 2009), supports the need for this change of terminology: 'occupation' is too innocuous.

Inclusion, a key theme of this study in relation to children with autism, is only possible when attention is given to the voices, perceptions, rights, wishes of the group to be included, be it children with autism or the Palestinian people. Disregard for Palestinian voices is not new. The history of the Palestinian people is characterised by lack of concern for Palestinian voices. Startlingly so in the early days of the displacement of the Palestinians from their lands in 1948, when a memorandum passing through the British Cabinet just after the Balfour Declaration offers a staggering example of the total disregard for the Arab inhabitants of Palestine at the time of the British Mandate:

For in Palestine we do not propose even to go through the form of consulting the wishes of the present inhabitants of the country [ ..... ]. The four great powers are committed to Zionism and Zionism, be it right or wrong, good or bad, is rooted in age-long tradition, in present needs, in future hopes, of far

profounder import than the desires and prejudices of the 700,000 Arabs who now inhabit that ancient land (cited in Said, 1979:16-17).

This 'narrow orientalist grasp on the Arabs as lesser beings with lesser or no rights' (Baroud, 2013) is a model that was 'borrowed and amply applied by the Zionists' (ibid). Baroud (2014b) shows us how Palestinians are still excluded from the discourse relating to them, saying 'it is unfathomable that Palestinians are still largely excluded from shaping their own discourse'. Exclusion of Palestinian voices allows for damaging misrepresentation of the Palestinians within international media (Chomsky, 2014). Public opinion in 'free-market' democracies is 'manufactured just like any other mass-market product - soap, switches or sliced bread' (Roy, 2004 p43). Israeli expertise with 'hasbara'<sup>4</sup> is used to present pro-Zionist accounts of situations in the region (Chomsky, 2010). Another problem for Palestinians is a negative perception of Islam in the West (Baroud, 2014a) as well as a readiness to interpret support for the Palestinian perspective or criticism of Israel as 'anti-semitic' (Rose, 2014; Tutu, 2014). A new worrying aspect of hasbara, it seems to me, is a development in the Israeli narrative whereby they characterise Palestinian resistance to oppression as extremist Islamic jihad which then allows Israel to claim that it is standing with the western world in the struggle against terrorism (BBC, 2014; Pappé, 2014).

These issues are pertinent the context of my research but the complexity invites greater attention than falls within the scope of this study. Nevertheless, in my research I have kept in mind the need to listen to and understand concerns expressed by Palestinians themselves. An iconic image for Palestinians is that of

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<sup>4</sup> Hasbara is an Israeli word that means 'explanation' and is also a euphemism for 'propaganda'. It refers to the dissemination of positive information about Israel.



Handala (Figure 5), a cartoon character created by Naji Al Ali who was subsequently assassinated in London in 1987. Handala is a voiceless, faceless figure whose silent observation questions the status quo and challenges injustices and ironies in the political landscapes depicted in Ali's cartoons. Handala is solitary, isolated, a part of society but excluded from it. For me, Handala is Palestine, silenced, faceless, excluded, poor. As an image of exclusion, I would like to return again to Handala, an excluded child whose rights are not recognised, when talking about some of the world's children with autism. Despite the injustices described here, Palestinians cannot be dismissed as mere victims of their circumstances, and the next few paragraphs describe their creative resistance, another important aspect of the background to my research.



Figure 5: Handala, created by Naja Al Ali

## **2.4 Palestinian solidarity and the Boycott, Divestment and Sanctions (BDS)**

### **Movement**

Palestinian agency and resistance in the face of oppression are strongly present and 'collective spirit is tangible everywhere you find Palestinians' (Nabulsi, 2014).

Moughrabi (2006) attests to 'high levels of social solidarity' and a 'spirit of creative resistance' amongst Palestinians. The BDS movement, denounced by some (Schama, 2006) as misguided, has attracted increasing support across the globe. There were more than 60,000 signatories to a recent petition (BDS, 2014) calling for sanctions against Israel. Baroud (2013) describes how the use of boycott has grown out of 'indigenous roots within Palestine's history of resistance against oppression'. Desmond Tutu (2013) suggests that the BDS movement can, as with South Africa, lead to a tipping point in Palestine's struggle for justice and liberation, adding that if we wait for western governments to act we'll wait forever. Pappe (2013) also sees BDS as the 'most powerful and constructive tool available'. As an Israeli activist he had sought transformation from within, but became convinced that there was no prospect of this within the foreseeable future. The BDS campaign, as well as the Palestinian Campaign for the Academic and Cultural Boycott of Israel (PACBI) brings together academics, artists and thinkers such as Ken Loach (2013), Iain Banks (2013), Omar Barghouti (2013) and others who have written in support or taken high-profile action, including many prominent Israeli authors, actors and directors (Wikipedia, 2014). Dr Jumana Odeh, a respected Palestinian medical doctor, eloquently explains her principled decision not to collaborate with her Israeli counterparts:

I refuse to take the role of a victim. I continue to believe that I'm rather a survivor of an ugly, paranoid, and temporary occupier and a fighter against the injustice of the situation..... I feel angry, frustrated, and disgusted... I always know why the occupiers are trying to break our spirit, but do they really know why they are doing so? Israeli doctors should realise that there is no way that they will be accepted by the international medical community in general, and the Arab medical community in particular, until the Palestinian people get their

rights to self-determination, which starts with ending the occupation (Odeh, 2010, P.17).

BDS is necessary because the so-called 'peace process' is a 'misleading and humiliating farce' (Tim Llewellyn, cited in Pilger, 2002:139), and my ethical position is to support BDS and PACBI, believing that this form of resistance might eventually win through<sup>5</sup>. For this reason, although my research takes place in close proximity to others in the Israeli community who are working with children with autism, opportunities have not been sought for liaison during the conduct of the research. It is against this background of political insecurity that I now discuss the Palestine-related literature on education, disability and autism.

## **2.5 Education in Palestine**

'The mere creation of an education system in such fragmented circumstances is remarkable'. (Nicolai, 2007:22)

Without an understanding of the background of occupation, oppression and disruption to daily life there can be no comprehension of education in Palestine today (Gumpel & Awartani, 2003). Education, like all other aspects of Palestinian life, has been affected by the occupation. This section describes the notable progress made towards building and developing an education system for Palestine's children.

Goldman et al. (2005) and Nicolai (2007) give useful overviews of the historical development of education in Palestine starting with four centuries of Ottoman rule. The British Mandate (1920-48) imposed an imported curriculum that ignored Palestinian identity, as had the preceding Ottoman rule. Following the Nakbah and the creation of Israel in 1948 Palestine was administered in two parts: Gaza was

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<sup>5</sup>136 (70.5%) of the member states of the United Nations and 2 non-member states have recognised the State of Palestine (United Nations, 2012)

administered by Egypt and the West Bank by Jordan, with no coordination between the two and, again, school curricula were externally imposed. At this time too, the United Nations Relief and Works Agency (UNRWA) set up schools for the thousands of refugee children. Today, UNRWA continues to work with over five million Palestinian refugees inside Palestine and within neighbouring countries. Following the six day war in 1967 Israel assumed control of aspects of governance they considered related to security and that included schools. Education at this time was under-resourced and undeveloped. During the Intifada of 1987-93 schools and universities were seen as centres of active political resistances and there were frequent closures. Universities were also closed completely from 1988-1990. At this time communities organised alternative arrangements for their children, thus starting what became a dynamic network of non-government educational alternatives. It was not until after the Oslo peace accords in 1994 that the Palestinian Authority was formed and progress towards a Palestinian education system began, hampered by fiscal challenges. The Al-Aqsa Intifada of 2000-2004 undermined progress that had been made: there was shell damage to many schools, universities and administration centres and many schools were turned into military bases or detention centres. With the building of the separation wall<sup>6</sup> which began in 2002, twenty two localities were separated from their schools by the wall. Although the legacy of this tumultuous past is the backdrop for my study, the spirit of 'a people who do not care to live on their knees' (Nabulsi, 2014) shines through in the literature about the current educational landscape. Throughout sixty eight years of dispossession and forty seven years of

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<sup>6</sup> 'In 2000 Israel approved the first project to build a "barrier". Construction of the Wall, including land confiscation and the uprooting of trees, began in 2002. When completed, the Wall and its associated regime will de facto annex some 46% of the West Bank, isolating communities into Bantustans, ghettos and "military zones"'. (Stop the Wall Campaign, 2010).

occupation by Israel, Palestinians have held on to a belief in the importance of education (Nicolai, 2007). In the quest for political autonomy and social stability, good education has been viewed as an important part of building society (Van Dyke & Randall, 2002) and a strong nation (Gumpel, 2003). Despite enormous difficulties (Nicolai, 2007; UNICEF, 2010; Morrison, 2010), much has been achieved and the creation of an education system within the fractured geography of the occupied territories of Palestine has been remarkable (Karlsson, 2004; Nicolai, 2007; World Bank, 2006). Educational development in Palestine is exceptional in that it is one of the few places in the world where a Ministry of Education is being created starting with a blank page (UNESCO, 2002). The Palestinian Ministry of Education was created in August 1994, five months after the formation of the Palestinian Authority (PA), following the Oslo Accords. Both girls and boys are educated and there are high adult literacy levels: 96.3% for men and 87.4% for women (Goldman et al., 2005). Education here is valued and Palestinians have been considered to be 'one of the most highly educated groups in the Arab world' (Pappe, 2006:150).

The PA provides mandatory education at Grades 1 to 10 and optional 'secondary education' at Grades 11 and 12 culminating with the Tawjihi general examination. Government schools tend to be quite small by international standards, with resource implications. One factor contributing to the tendency towards small schools is the predominance of single-sex schools, as only 31% of schools are co-educational (UNESCO, 2011), although there have been increasing moves by the Ministry of Education and Higher Education (MoEHE) to open co-educational facilities (Nicolai, 2007). Class size is on average 35<sup>7</sup> (UNESCO, 2011), a factor which Farrell (2007)

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<sup>7</sup> West Bank: 30 and Gaza: 40

found worked against inclusion of children with additional needs, although Farrell found that class size was 40 on average (ibid). It is a mark of the value given to education by Palestinian society that, in the West Bank, enrolment in secondary education (Grades 11 and 12) is above 90% compared to 70% in MENA (Middle East and Africa) as a whole (PASSIA, 2011). Progression into higher and further education for 18-21 year olds is 44% which is high by international comparisons (in 2003 the average in other Arab states was 15%) (UNESCO, 2011). There are 11 universities, 11 technical colleges and 19 community colleges providing post-secondary education and training in Palestine (PASSIA, 2011).

As well as education provided for 66.5% of children by MOEHE, 24.5% are educated in UNRWA schools<sup>8</sup> and 9% in private schools. A more detailed breakdown is given in Table 1.

Region	Supervising Authority	Grand Total			Basic			Secondary		
		Total	Males	Females	Total	Males	Females	Total	Males	Females
Palestine	Total	1,151,702	571,908	579,794	1,009,639	508,904	500,735	142,063	63,004	79,059
	Government	764,219	369,302	394,917	629,038	310,011	319,027	135,181	59,291	75,890
	UNRWA	282,784	140,797	141,987	282,784	140,797	141,987	.	.	.
	Private	104,699	61,809	42,890	97,817	58,096	39,721	6,882	3,713	3,169
West Bank	Total	677,004	334,536	342,468	593,328	298,050	295,278	83,676	36,486	47,190
	Government	537,306	261,726	275,580	459,925	228,566	231,359	77,381	3,3160	4,4221
	UNRWA	51,270	21,323	29,947	51,270	21,323	29,947	.	.	.
	Private	88,428	51,487	36,941	82,133	48,161	33,972	6,295	3,326	2,969
Gaza Strip	Total	474,698	237,372	237,326	416,311	210,854	205,457	58,387	26,518	31,869
	Government	226,913	107,576	119,337	169,113	81,445	87,668	57,800	26,131	31,669
	UNRWA	231,514	119,474	112,040	231,514	119,474	112,040	.	.	.
	Private	16,271	10,322	5,949	15,684	9,935	5,749	587	387	200

Table 1: Number of Students in Schools by Region, Supervising Authority, Stage and Sex (PCBS (Palestine Central Bureau of Statistics), 2014)

<sup>8</sup> In Gaza about 50% of children attend UNRWA schools (PCBS 2014)

The situation is even more complicated in East Jerusalem, the Palestinian part of the disputed capital, where four different authorities govern the education system for Arabs. The Jerusalem Education Administration (JEA), a joint body of the Jerusalem municipality and the Israeli Ministry of Education, runs 50 schools attended by 48% (about 40,000) of Palestinian children in the city (Kestler-D'Amours, 2012). The remaining children attend Islamic WAQF<sup>9</sup> schools, UNRWA schools or private schools. There is concern that there is inadequate provision of school places and inadequate quality of education and that this is in violation of the rights of Palestinian children in Jerusalem to education (Kestler-D'Amours, 2012). One study comparing Arab and Jewish populations suggests that long-term historical differences between the two groups and discriminatory practices towards Arabs are important factors in explanations of disparities in educational attainment (Okun & Friedlander, 2005). Baroud (2010), a Palestinian commentator, while recognising the devastating impact of the occupation on education in Palestine, does not absolve the PA of a share of blame because of the political wrangling between competing factions. Moughrabi (2006) also points a finger at a corrupt and poorly managed political system but balances this against a strong spirit of creative resistance amongst Palestinians.

As well as recognising achievements, my study has sought an understanding of the barriers to educational progress in Palestine. Gumpel & Awartani (2003) found that 'severe financial constraints' (p35) had imposed limitations on educational development and that Palestine was 'reeling under the pernicious effect of poverty, unemployment, poor health services and, primarily, military occupation' (p43), with a

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<sup>9</sup> WAQF – Islamic charitable trust.

negative impact on education and inclusion. Financial constraints, as reported in the literature by Palestinian and international researchers alike, have led to: the poor state of school buildings (Reimers, 2012; UNICEF, 2011); minimal resources (Wahbeh, 2011); lack of ICT provision and knowhow (Wahbeh, 2006; Pacetti, 2008); geographical fragmentation (Nicolai, 2007); a donor-dependent system (Goldman et al., 2005) that has substantially shaped education policy in ways that inhibit a broad vision of teacher education (Shinn, 2012); complicated and centralised bureaucracy and a long, unmanageable curriculum (NAD, 2010); and a supervisory system that is both adversarial (Khaldi & Wahbeh, 2002) and disempowering (Wahbeh, 2011). In addition there is a lack of a clear shared philosophy (Van Dyke & Randall, 2002) and low teacher morale (Khaldi & Wahbeh, 2002; Nicolai, 2007). This leads me to consider the impact on teaching and learning, an issue that is important to my research both in relation to the children with autism and in relation to the teaching and learning styles of the teachers themselves who are the product of the Palestinian education system, and alongside whom my research takes place.

Pedagogy in Palestinian schools is largely traditional and didactic in style (Al-Ramahi & Davies, 2002; Farrell, 2007; Karlsson, 2004; Khaldi & Wahbeh, 2002). Although teachers have been found to have good subject knowledge (Wahbeh, 2011), classroom observation of teachers found teacher-centred approaches, lecture, dictation, note taking and rote memorisation to be the predominant approaches to teaching (UNICEF, 2011). So whereas MOEHE wishes to implement a curriculum to develop critical thinking and high order thinking skills (UNESCO, 2011) teachers themselves may not have had the opportunity to develop these thinking skills (Van



Dyke & Randall, 2002), having themselves been educated in a system that did not foster this. One of the drawbacks of a rigid, rote-learning pedagogy where learners are passive is that it fails to prepare children for roles where creativity and flexibility are needed. This was found to be the case by Jentoft (2009) in an action research study in Gaza involving occupational therapists whose training, under exceptionally difficult conditions, included learning about autism. The study found that the school education her participants had received had primed them to be passive learners, unprepared for a professional role that needed them to be (like teachers) reflective, creative and flexible in the face of complex challenges. The Tawjihi, the final examination at the end of compulsory schooling, has been criticised for being a strong determinant of rigid approaches to teaching and learning (Nicolai, 2007; UNESCO, 2011) by encouraging children to memorise facts rather than think creatively. This may also be true of Palestinian universities where 'high grades in exams are achieved by parroting the lecturers' ideas, not by challenging them' (Kalman, 2014). I would add, to fend off accusations of cultural hegemony, that this may well be true of educational institutions in the UK and elsewhere.

Teacher education in Palestine is pertinent to my research, as I consider how teachers and practitioners can be empowered with knowledge and skills to be able to include children with autism. Since the formation of MOEHE there has been strong interest in pedagogy and vigorous debate about how education should be improved (Goldman et al., 2005). However, the literature suggests that teacher education in Palestine is inadequate to redress the difficulties (Khaldi & Wahbeh, 2002). Attempts to address the issue have been 'piecemeal' (Nicolai, 2007:99) as 'both in-service and pre-service teacher training have been implemented in a fragmented manner,

focused on delivery of separate courses rather than being built around a comprehensive skill set for teachers' (Nicolai, 2007:106). Opportunities have been missed to exploit the advantages of e-learning that would help to overcome the geographical fragmentation within Palestine (Shraim, 2012). Van Dyke & Randall (2002) found a lack of dialogue and collaboration amongst educators and Al-Ramahdi and Davies (2002) indicated a lack of autonomy amongst teachers. Khalili's study (2010) concluded that notions of student-centred learning are not well understood and that teacher training encouraged new teachers to see their role as imparting a body of knowledge and procedures. Khaldi & Wahbeh (2002), in a forward-looking study, found a 'lack of confidence, skills and creativity among teachers' (p199) and called for them to 'reconceptualise their role' (p193) and view themselves as producers of knowledge and to share their knowledge and skills. The authors were critical of a MOEHE requirement for teachers to attend 60 hours of INSET annually, often during vacation, when 'European and American volunteers lecture the teachers about methodologies without practical application to Palestinian classrooms' (p203). A National Teacher Education Strategy was launched by MOEHE in 2008 (UNESCO, 2011), followed by a Commission for developing the teaching profession in 2009 (ibid), with the aim of developing teaching methodologies that would be student-centred, reflective and activity-based. A subsequent study (Wahbeh, 2011) found that centralised control over educational approaches in Palestinian schools worked against the cross-fertilisation of ideas between teachers and called for opportunities for teachers to share ideas by building communities of practice. With reference to the shining example of Ni'lin Teachers' Centre, which was set up by AM Qattan Foundation to extend the educational and cultural horizons of

teachers in the West Bank, Wahbeh's study found a need for professional development opportunities centred on reflective practice, and that teacher empowerment, based on collegial knowledge exchange, would lead to improved quality of education in Palestine (AM Qattan Foundation, 2014).

Wahbeh's proposals resonate well with studies (Wenger, 1998; Wenger et al., 2002; Guldberg et al., 2013) that show how the CoP model can provide an effective social forum for learning by sharing and shaping a body of knowledge and skills within a given domain of shared interest, tapping into explicit and, perhaps more significantly, tacit knowledge. It is an approach that can empower participants by valuing their existing knowledge and skills while enabling them to develop through peer-to-peer collaboration. Wenger (2009) suggests that this may provide an attractive alternative to the traditional transmission of knowledge from north to south, by building on, rather than supplanting existing culturally appropriate knowledge. I return to the theoretical framework of the CoP model in Chapter 3 and more fully in Chapter 5. As well as challenges relating to education, the issue of disability in Palestine is also pertinent to my study and I now turn to the literature relating to this.

## **2.6 Disability in Palestine**

'There are two separation walls that menace Palestinian society; one is that infamous grey structure that denies every Palestinian the basic human right to live in dignity, and the other is the lesser-known invisible wall that pushes Palestinians with disabilities even further away from this right' (Zayed, 2014:1).

Before looking at educational provision for children with differences and disabilities, I explore the issue of disability in the wider Palestinian society. Negative attitudes towards disability can have a harmful impact on the lives of those with disabilities and

9.5% of disabled adults in the West Bank said that they avoided social engagement for this reason (PCBS, 2011). In the Arabic speaking region words to denote disability are reported to be derogatory and pejorative and often used as swear words (Al-Thani, 2006). However, attitudes may vary according to the nature of the disability. As mentioned previously, the first Intifada, 1987-93, left Palestine with an estimated 10,000 disabled people, mainly young boys. One positive outcome of this is that people with disabilities, at least those with physical disabilities, are seen as heroes (Karlsson, 2004). In Arab societies generally priority is given to motor disabilities over other disabilities (Opdal et al., 2001). However, this positive acceptance does not seem to extend to other forms of disability. It is sometimes seen as shameful to have a child with a disability and such children are commonly kept hidden away at home as families fear that the community will reject them (Gumpel & Awartani, 2003). Such a child, it is thought, casts blight on the marriage prospects of siblings (ibid), as prospective partners would fear that their own offspring might be similarly afflicted. There are anecdotal accounts of appalling abuse of children with autism and those with learning difficulties (Hviid, 2011). However, with greater awareness perceptions are changing towards disability and the rights of the child (Gumpel & Awartani, 2003). Indeed, Jarar (2014) reported a 'massive increase' in debate about disability rights in the last decade and (Al-Thani, 2006) was 'optimistic' that throughout the Arab region there was growing interest in the issue although she reported that attitudes are more likely to be negative towards 'psycho-social' disabilities, as borne out by Dababnah and Parish (2013) who found very negative attitudes towards autistic children and their families. Lifshitz et al. (2004), seeing Palestinian society as collectivist and concerned with the national good, found that

Palestinians perceived disability as shameful for the family. There was, she said, a philosophy of passive acceptance which perceived a person with disabilities as incapable of development and therefore entitled only to nursing and medical care within the hamula (extended family). However Lifshitz (ibid) did suggest that attitudes are shifting, especially since the passing of the Disability Rights Act in 1999 (Palestinian National Authority, 1999). Al-Thani (2006) emphasised that attitudes towards disability did not stem from Islamic religious beliefs and that within Islamic thinking disability is 'neither a blessing nor a curse'. Perceptions of disability and difference impact on attitudes towards educational inclusion and I return again to the small body of studies about educational inclusion in Palestine in Chapter 3,

One positive initiative in relation to disability has been the introduction of the community-based rehabilitation (CBR) programme, established in 1990 to meet the needs of children and adults with disabilities and subsequently supported with financial and technical assistance from Diakonia, a Swedish charity and the Norwegian Association of Disabled (NAD). The approach is a move away from institutional, long-term care to the dissemination of knowledge and skills to the support network for people with disabilities, with professionals training non-professionals. The programme covers 60% of the population in the Occupied Palestinian Territories (OPT), mainly in poor rural areas, and has reached more than 33,000 people with disabilities and their families (Nilsson & Qutteina, 2005). Summer camps for children have been a successful means of integrating children with disabilities into community recreational activities. Studies conclude that the CBR programme has had a major impact (Harami et al., 2010) and has greatly improved health care of people with disabilities. A study of the perspectives of people with

disabilities (Nilsson & Qutteina, 2005) found that the programme had 'empowered individuals and parents, improved basic daily living skills and coping mechanisms, reduced stigma and isolation and increased social inclusion'. However this is not borne out by Zayed (2009) who found widespread discrimination and negativity towards disability and reported that rather than a rights-based perspective, community based organisations held charitable or medical models of disability. One study (NAD, 2010) found no clear delineation of roles between CBR and MOEHE and that there was room to develop a more productive relationship. My research looks at community-based support for children with autism in Palestine and considers how this relates to government initiatives. An indication of how ideas about disability have progressed in Palestine is found in a current empowerment project (Burton et al., 2013) which is working with disabled people to bring about change in their communities by moving away from medical or charitable models of disability to emphasise a rights-based position. The researchers claim that the success of this action research study in bringing about positive change is due to its grass-roots, 'bottom-up' approach, distinguishing it from the many other 'top-down' disability projects that there have been in the region. The next section looks at education for children with disabilities in Palestine.

## **2.7 Education of children with disabilities / special needs in Palestine**

Palestinian law enshrines the right of children with disabilities to appropriate education (Palestinian National Authority, 1999), but many children with disabilities in Palestine miss out on education (Farrell, 2007). A statistical survey (PCBS, 2011) found that 'more than one third of disabled persons aged 15 years [and over] had never enrolled at school' (p13), and of those who did attend, 22.2% dropped out

because of their disability. The employment prospects of those with disabilities are poor and 87.3% of disabled adults do not work (ibid). SEN was seen as an emerging field in Palestine by Gumpel (2003) who found that much had been done in a short time and in unfavourable conditions since the Special Needs Department within the Palestinian Ministry of Education came into being in 1995. In 1999, Palestine became a signatory to the UNESCO Education for All initiative. There followed a largely complimentary report on education in the West Bank and Gaza (World Bank, 2006), which proposed that meeting the needs of children with disabilities and special educational needs should be a key objective in the next five-year education development plan. In 2008, the Ministry of Education promised that all children, including those with a disability would receive an education by 2015 (Ministry of Education and Higher Education, 2008). The intention to include children with different needs is clearly there but the capacity to do this has not kept pace. Opdal (2001) found a 'surprisingly high' positive attitude towards the inclusion of children with special needs but a lack of attention to SEN in initial teacher training and few subsequent opportunities for teachers to update their knowledge. Inclusion is a key theme in my research and I return to this issue in Chapter 3. I now attend more specifically to the education of children with autism.

## **2.8 Autism in Palestine**

There is growing awareness of autism although very little has been written about autism in the Palestinian context. Palestine's first specialised national disability survey (PCBS, 2011b) included 'autistic spectrum disorder', within the category of 'learning difficulties'. Prior to this the Child Statistics survey (PCBS, 2011a) made no reference to autism, whereas the survey that took place after the disability survey the

following year (PCBS, 2012) does allude to 'autistic spectrum disorder' and includes it within the definition of 'learning disability/ difficulty'. This points to growing interest in autism, although the categorisation of autism as a 'learning disability / difficulty' is problematic and may reflect the need for better understanding of this complex condition<sup>10</sup>. The disability categories used by PCBS also include 'communication disability', and as social communication is a key issue in autism, this compounds the problem of how to categorise it. A recent survey of the experiences of parents of children with autism in the West Bank (Dababnah & Parish, 2013) makes disturbing reading and powerfully highlights a need for better awareness of autism and a need for support for parents. The report finds a tendency to blame the mother for her child's perceived disability and to see conditions such as autism as a 'punishment from god'. A study carried out by post-graduate medical students at An-Najah University (Zayed & Banifadel, 2012) looked at autism-related provision in the West Bank. While there were isolated examples of beneficial practice, the overall picture showed a significant shortage of training to meet the needs of these children. Provision, such as it was, was mainly in the central and southern parts of the region. Although Zayed and Banifadel usefully looked at autism provision in the West Bank, this was viewed from a medical perspective in terms of diagnosis and care management. The issue of good autism practice in education was beyond the scope of their study.

The brevity of this part of my literature review is indicative of the lack of literature relating specifically to autism in Palestine. The two studies mentioned in the

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<sup>10</sup> For some children with autism it could be better to refer to 'learning difference' rather than a 'learning disability/ difficulty'. However, about half of the children who have autism will also have learning needs in addition to their autism.



preceding paragraph are notable for their rarity value. My searches found no evidence in the research literature of studies relating to educational practice and provision for children with autism in Palestine. This highlights a significant gap in the research literature and supports my perception, gained from discussions with teachers in the West Bank, that autism education is an undeveloped field in Palestine. Therefore I believe that my research has the potential to make a useful contribution to the development of good autism practice in Palestine. The absence of literature on autism education in Palestine means that it is timely to look at current practices and developments in relation to the education and inclusion (or otherwise) of children with autism in Palestine and to consider opportunities for teachers to gain knowledge and develop their practice in this field. Another gap in the literature on autism in Palestine is the autistic voice. Whereas in western countries autistic people have made an enormous contribution to the discourse relating to autism education, these voices seem non-existent in Palestine. So it becomes important to explore opportunities for knowledge sharing that includes autistic people and their parents, an issue discussed further in Chapter 5.

## **2.9 Conclusion and questions for my research**

Although ‘an end to the occupation and a permanent peace is the largest determinant in fulfilling Palestinian children’s right to education’ (Nicolai, 2007:131), my study tries to understand and work within the present constrained realities of Palestine. It is a context where community solidarity thrives and there is ambition for the future of children and communities despite the injustices. Education is important for Palestinians and remarkable progress has been made although there have been limited opportunities for the development of expertise within the teaching profession

in relation to inclusive practice. Attitudes have become more accepting of difference and disability and there is new interest in autism, matched by a lack of research and information. Given the dubious history of British colonialist interference in the affairs of Palestine, my research approach seeks to avoid the imposition of extraneous, unhelpful ideas about disability or diversity. I support the notion that the 'Palestinian people should become producers of knowledge rather than mere consumers of knowledge' (QCERD, 2012) and so my research asks: what do we have to learn from the Palestinian experience and how can Palestinians contribute to the international discourse on the educational inclusion of children with autism? The following chapter looks at the literature on educational inclusion and considers how this might relate to Palestine.

## **CHAPTER 3: INCLUSION: A REVIEW OF THE LITERATURE**

‘There is a historical pulse behind inclusive education and it is gaining in strength’ (Thomas & Vaughan, 2004:190)

### **3.1 Introduction**

A belief in inclusion has informed my own thinking and practice in education and my experiences as a grandmother of a child with cerebral palsy and of a child with autism, have led me to think close to home about the importance of social belonging and participation for all children, for the enrichment of all of us. However, there is a need to puzzle over what it means to ‘believe in inclusion’. In the UK 30% of children with autism, for example, are not included with their non-autistic peers (Charman et al., 2011). Is this the same as ‘exclusion’? Is ‘segregation different from ‘exclusion’ and if so how? Is it possible to champion inclusion but also feel that it is not right for everyone? Inclusion for some – is there any sense in that? In my role within the Access and Inclusion team where I worked, I sometimes advocated special schools for children with autism when, despite our efforts, their needs were not being met within mainstream. This contradictory belief in inclusion and a reluctant acceptance of a need for a form of segregation for some children has led me to challenge and develop my thinking about the issue of inclusion. An issue for this study is to consider what inclusion for children with autism in Palestine might look like and whether it might be different from inclusion within, say, the UK. In this chapter I map out these issues before looking more closely, in the following chapter, at inclusion in relation to autism.

### **3.2 The concept of inclusion**

Thomas and Vaughan (2004) place inclusive education (IE) firmly within a human rights framework, giving us the voices of Thomas Paine and Martin Luther-King in the

powerful opening of their book. Others too see IE as a cornerstone for human rights and social justice (Allan, 2008; Barton, 2000; Farrell & Ainscow, 2002; Roaf & Bines, 1989; Rustemier, 2002; Slee, 2000; UNESCO, 1994). Educational inclusion, it is argued, leads to social inclusion (UNESCO, 1994); segregation leads to further segregation (CSIE, 2003). In Palestine too, IE has been seen as a means to social inclusion (Harami, 2010). Booth & Ainscow (2011) persuasively call for the social cohesion and equity that inclusion can bring about. More than this, Thomas (2013b) reminds us that alienation, the failure of inclusion, is at the root of failure of some children to learn in our schools and drawing on the work of Dewey, Vygotsky and Lave and Wenger, shows us that social connection is important for learning. Thomas also demonstrates that in regions of greater social inequality and social exclusion there are more school casualties, making a strong argument, both educational and social, for inclusion. An international movement towards educational inclusion was given impetus by a world conference on special needs education in 1994, from which came the Salamanca statement (UNESCO, 1994) calling on the international community to endorse inclusive schooling and give all children access to regular schools, regardless of any special needs. Ninety two countries, including Palestine, signed the Salamanca statement. This principled commitment to inclusion and bringing all children into mainstream education is an enormous challenge if, as in the case of Palestine, the region is moving from a starting point of a minority of children with 'special needs' in mainstream education (Farrell, 2007; Palestinian Central Bureau of Statistics and Ministry of Social Affairs, 2011). The magnitude of the challenge together with an unclear understanding of inclusion (Farrell, 2007) may have sometimes led to the introduction of integration rather than inclusion. The

distinction between the two, says Jordan (2008) is that inclusion, on the one hand, requires flexibility, good teaching ability, adaptation, understanding of diversity whereas integration places a child in a setting without addressing his needs.

If inclusion is understood simplistically and seen as an end in itself rather than a process, there is a danger of approaches that are primarily to do with show-casing a dogma of social justice. An illustration of this is found in the writing of Ware (1998) which I refer to at some length because it helped me to understand an approach that I wish to resist. Ware tells us that:

Any time you try to include a student with disabilities in the classroom – by the very act of having them in the classroom – you’re making a statement of values. It’s like when you have something in your home that you set out, you say, ‘this is of value to me and I want it to be part of my everyday life. I want it to be here because it brings me pleasure or because it is functional, or because it is somehow important to me’. [.....] Any time you bring a student with disabilities into your classroom, you’re saying, ‘I value humanity, I value an open attitude, I believe all persons are created equal, and I’m going to live up to that ... to walk the walk you know?’ (p.42)

This illustrates a danger that may be inherent within a rigidly rights-based approach. The danger is that the focus, as here, is to do with parading the laudable values of the ‘includer’ rather than thinking about the needs of the ‘includee’ and what it is that they are being included into. The solipsism of comparing a student in your class to a status symbol in your home, suggests that the rights of the child to an inclusive education are of secondary importance to the writer’s right to demonstrate her worthy values. Rather than ‘walk the walk’, there is a possibility here that the author of this piece is merely ‘strutting her stuff’. A different stance is taken by Allan (2008) who suggests that the need is to ‘complicate rather than explicate’ (p156), to delve into the messy complexities of inclusion rather than settle for a superficial explanation of

what it is. Despite the difficulties of definition, there are voices that reassure us that IE is worth striving for (Allan, 2008) and that effective IE is possible (Ainscow, 2011). Barton (2005 cited in Allan, 2008) calls for hope to be at the centre of the struggle for inclusion and a belief that change is possible, despite difficulties and barriers.

Hope on its own is not enough, of course, but it is worth holding on to because the obstacles are many. For example, the raising standards agenda in UK schools can work against inclusion (Farrell & Ainscow, 2002), when schools feel a danger that the presence of children with additional needs will have a detrimental effect on their overall results. Indications suggest, however, that education authorities with strong inclusion policies, such as Newham, challenge the idea that the inclusion of children with additional needs works against raising standards in schools (Corbett, 2000). It has been persuasively argued that the two are not incompatible where there is a will to do both (Clough and Corbett, 2000; Florian, 2008). Finland may have the best performing school system in the world and it also has a philosophy of inclusion and equity underlying the whole system (Thomas, 2013b). So fear becomes a barrier to inclusion, fear that inclusion will lower standards. Inclusion is about change, says Corbett (2000) and our fear of change is simply an obstacle to be overcome.

There are also other forces that work against inclusion. Special needs educators are sometimes seen to be behind a failure to promote IE, either because of their belief in segregated provision or because of their lack of understanding of IE. A broad, values based perspective has eluded many thinkers from within the field of special needs education and led to their 'appalling ignorance of the scope of inclusive education' (Slee, 2001 cited in Allan, 2008:120). The Centre for Studies on Inclusive Education (CSIE, 2003) provides a hard-hitting list of arguments against segregated schooling:

lack of evidence of benefits for children who attend them; poor educational and social outcomes; perpetuation of discrimination, prejudice and stigma; depression, dependency and isolation. As well as this, they claim that segregation stifles teacher creativity in responding to diversity. Florian (2000), Tomlinson (1982) as well as Goffman (1968) before them, see segregated provision in special institutions as serving the needs not of the children and people in them, but of the wider society. Throughout the world, claims Oliver (1995), the history of the provision of segregated education has been one of abject failure. Rustemier (2002) asserts that segregation is based on a false belief that it is not possible to include some children and she asserts that this can be disproved. However, there is a schism between those inclusionists who believe that inclusion is incompatible with the retention of special schools (Booth, 1998 (cited in Florian 2008); CSIE, 2003; Oliver, 1995; Slee, 2001 ) and those who take an approach that is more cautious, perhaps less rigid (Corbett, 2000; Mittler, 2000). Those who would abolish special schools have powerful arguments on their side (CSIE, 2003) but voices from the autism world and my own experience draws me back to the more tentative voice of Allan in her aptly named 'Inconclusive Education' (Allan 2000) that tells us that inclusion is never complete but always a working towards.

Another obstacle to inclusion can be found in the way we conceptualise difference. Inclusive education, for some (Ainscow, 2002; Slee, 2000; Thomas & Loxley, 2001) demands a move away from a medical model that focuses on individual 'deficits' and a move towards a social model that looks at attitude, environmental barriers to participation and accepts that meeting students' needs is a shared responsibility. In Chapter 4 the medical and social models of disability are discussed in relation to

autism and I argue against a rigid medical model which pathologises difference. As Slee (2000) puts it, this approach 'lets us off the hook' (p.127) as we can locate the 'problem' in the child. I warm to his challenge of 'why not explore the deep pathology of schooling' instead (p.127). Lilley (2014) does just this when she explores 'autism inclusion disorder' in Australian schools and finds that they have deficits in social communication and interaction as well as rigidity of thought relating to behaviour management. She concludes that it is the schools that need to change.

Yet another obstacle to inclusion is to be found in the words we use, as language can be exclusionary. Ainscow (2000) moves away from terminology such as 'SEN' and talks instead about 'difference'; Booth & Ainscow (1998) pick out 'SEN provision' as an example of 'exclusionary terminology' (p.65) in their critique of Allan's case study (Allan 1998); their contention is that such terminology distances us from a group of students. This sense that the language we use can reflect deeply embedded negative and deficit related beliefs is echoed by Thomas (2013b) who calls for a new kind of thinking about IE and a recognition that inclusion is about all children not just those with disabilities. Further, he says that it is 'recognition, respect and identity that are most important for young people's success at school, not the identification of need, nor help' (p.484). Slee (2001) takes the notion of identification of difference as a barrier to inclusion further and asserts that teachers do not need to know about 'syndromes and disorders'. He believes that such knowledge in no way helps teachers to be more inclusive. With both Thomas and Slee there may be a danger of overlooking educationally important differences and while I feel wholly supportive of the need for schools to 'enable community and encourage students' belief in themselves as members of such a community' (Thomas, 2013b:486), my experience



and my reading lead me to resist an understanding of Thomas's words to mean that identification of need and help are of no importance. Rather, I align my thinking with that of Florian (2008) who writes that, 'a rejection of models of provision that depend on identifying individual differences does not mean that there are no educationally important differences' (p.206), and in Chapter 4, I discuss what the literature on autism education brings to the inclusion discourse and consider whether the process of identify – assess – diagnose – help, rather than obstructing inclusion might, for the child with autism at least, be a respectful step towards enabling inclusion. A challenge to knowing whether or not the process of 'identification, assessment, diagnosis and help' contributes to greater inclusion is partly that each of those four stages in the process is open to a wide range of procedural and situational variables. Moreover, we lack hard evidence of what actually works in inclusive practice (Goransson & Nilholm, 2014) and it is insufficient to simply claim that an environment has become more inclusive. What we need is research to provide objective indicators of what works (ibid). Goransson & Nilholm (ibid) also propose that a major obstacle is the lack of conceptual clarity of what inclusion is and they identify research findings of four distinct ways in which inclusion is conceptualised:

- a) The placement of pupils with disabilities in mainstream classrooms
- b) Meeting the social and academic needs of pupils with disabilities
- c) Meeting the social and academic needs of all pupils
- d) The creation of communities

They place these categories in a hierarchical relationship whereby each definition includes previous definitions in the list so, for example, a view of inclusion that entails meeting the social and academic needs of all pupils (c) presupposes meeting the needs of pupils with disabilities (b) and the placement of pupils with disabilities in

mainstream classrooms (a). The last category (d) presupposes the other three, although the characteristics and values of the community can vary. This analysis is a useful basis for thinking about how a concept of inclusion impacts on practice. An even greater obstacle, though, may be the lack of research evidence of how schools and teachers can bring about inclusion and these authors call for robust research into this important field. In response to Goranssen & Nilholm, Florian (2014) agrees with the need capture evidence of IE and offers a framework, the inclusive pedagogical approach in action (IPAA), designed for this purpose and useable in differing contexts. The IPAA identifies three basic assumptions about inclusion:

1. Difference is accounted for as an essential aspect of human development in and conceptualisation of learning
  2. Teachers must believe they are qualified / capable of teaching all children
  3. Teachers continually develop creative new ways of working with others
- (Florian, 2014:7)

Florian's framework gives pointers to evidence of good practice in IE. For example, (in relation to the first assumption in this list) the framework specifies:

Creating environments for learning with opportunities that are made available for everyone so that all learners are able to participate in classroom life  
(Florian, 2014:7)

This, and the other indicators in the framework, usefully describe what inclusion might look like but do not tell us how it can be achieved. They give the 'what' but not the 'how'. In Chapter 4 (Autism and Education) I find examples of where the literature on autism and inclusion focuses on the 'how' of inclusion. These issues are strongly pertinent to my research endeavour as I position my own understanding of inclusive autism education at the same time as seeking to gain understanding of perceptions and practices in Palestine. I now look at the literature about IE in Palestine.

### **3.3 Educational Inclusion in Palestine**

This section looks at literature relating to inclusion in Palestine but first considers the wider issue of perspectives and practice about inclusion in differing cultures. Booth & Ainscow (1998) call attention to the possibilities of developing our understanding of educational inclusion through research into perspectives from across the world, especially from countries with disparate cultures and economies. However, rather than an international sharing of perspectives, historically there has been an uncritical movement of ideas on inclusion from north to south (Miles, 2002). Wolf (cited in Thomas, 2013a) laments the tendency of developing countries to 'expensively copy the achievement-orientated, educationally barren models from the west' (p108). Damage results from the introduction of approaches which are alien to the culture into which they are imported (Thomas, 2013b). Kisjani (1998) tells us how approaches imported into African countries undermined the traditional 'indigenous customary education' whereby all children were included and taught about the things that mattered to the community, and instead of this, those with disabilities were placed in asylums and, later, special schools. The change is now seen as having been a disaster and IE is now seen partly as a reassertion of the old ways. There is a worldwide trend towards inclusion (Farrell & Ainscow, 2002), and it matters that each country finds its own route as each varies in its history and culture (Mittler, 2003; Malki, 1997). Not only that, it may well be that looking at (and I would add 'working with') other cultures can help us clarify what we mean by IE (Corbett, 2000). Perhaps, Thomas (2013b) suggests, parts of the developing world can stand as exemplars to the north. Just as diversity of students in schools can be celebrated and seen as

enriching, rather than problematic, so a diversity of perspectives on inclusion can, I suggest, be a spur for new creative thinking about inclusion.

Foreign aid to developing countries, one of the catalysts for imposing alien agendas, can bring negative outcomes as well as positive benefits and, as Nes (2003) suggests, can reinforce a 'them and us' way of thinking which can ultimately maintain exclusionary practices. Commenting on UNESCO programmes for IE in former Yugoslavia, Cross (2003) questions the right of outsiders who lack understanding of local complexities to suggest how a country recovering from turmoil might proceed. For my research there are cautionary messages here when thinking about these issues in the Palestinian context, so while I have reflected positively on the value of multiple perspectives, I also side with the view that 'inclusive education is really a process of people enquiring into their own context to see how it can be developed and it is a process of growth' (Clough & Corbett, 2000:39).

Despite Palestine's growing acceptance of the rights of people who are different or disabled, as discussed in the previous chapter, and their signing of the Salamanca agreement (UNESCO, 1994), and notwithstanding the fact that Palestinian law enshrines the right of children with disabilities to an appropriate education (Palestinian National Authority, 1999), many children with disabilities in Palestine still miss out on education (Farrell, 2007). A search in the literature for the underlying attitudes of educators towards inclusion in Palestine fell short of being conclusive. Lifshitz (2004), comparing attitudes of teachers in Palestine with those in Israel, found that Israeli teachers showed greater willingness to include pupils with special needs, although attitudes within Palestine were changing. Established approaches to teaching in Palestine tended to see children with disabilities as obstructing the

important task of education to the detriment of society as a whole (ibid). A different view is given by Opdal et al. (2001) who found that 60% of the teachers believed that children with SEN should have the opportunity to attend mainstream schools and 90% said public schools should change to meet the needs of children with SEN and disabilities. Goldman et al. (2005) found that a lack of capacity for identification of children with special needs was a particular weakness in Palestine. A more recent and encouraging report on progress towards inclusion in Palestine (NAD, 2010) found that much progress had been made but ongoing constraints included traditional inflexible teaching methods, a demanding curriculum and lack of funding. The report noted attitudinal changes that were conducive to inclusion, although this was characterised by a charitable perspective rather than a rights-based perspective. The sparse literature offers a few shining individual reports of inclusive educational practice in Palestine. Hawash (1998) describes a forward-looking project to promote inclusion in a Palestinian school by developing peer support, adapting the environment, training teachers and involving parents; Abualia (2006) describes developing a welcoming environment to encourage inclusion, working in extremely difficult circumstances with marginalised Bedouin communities in the West Bank.

As a first strategic step at government level to bring in IE for children with different abilities, Palestine launched a National Programme for the Inclusion of Children with Visual Impairments in April 2014 (CBM, 2014). The intention to include children with different needs is clearly there but the capacity has not kept pace. A consultancy report (Farrell, 2007) found encouraging signs that the quality of IE was improving, but that it was under-resourced, and teachers were ill-informed about the meaning of inclusion. Farrell offered a definition of inclusion that was about overcoming barriers

at organisational as well as classroom level to address the individual needs of all pupils, although he recognised this to be an idealised model that has not been fully realised anywhere in the world. Although, elsewhere, his understanding of the needs of children with autism may be questionable (Jordan, 2011), this does not detract from the potential usefulness of his recommendations for the professional development of teachers and increased capacity and resourcing as means of promoting progress towards inclusion in Palestine. This leads me to consider the fundamental importance of teachers and their professional development.

### **3.4 Inclusion, teachers and developing inclusive practice**

Florian (2008) writes that teacher behaviour makes or breaks IE. Teachers, she says, are skilled at making constant multiple decisions in response to all kinds of differences between students and sometimes the student's needs exceed the teacher's capacity to respond. To describe a teacher's capacity for professional development Florian uses a model (Fig. 5) taken from Rouse (2008 cited in Florian, 2008) to show how knowledge, beliefs and practice interact. Any two of the dimensions will influence the third: if the teacher believes in rights and is willing to try, then her knowledge of inclusive practice will develop, and so on. Florian believes the future of IE should focus on practice and for this, teacher education is important: concepts of normalcy and beliefs about disability need to be challenged and teachers need to be disabused of the notion that they are not qualified to teach children with additional needs.

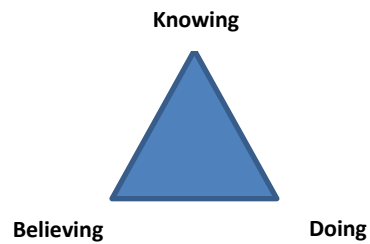


Figure 6: A model for teacher development – any two of the dimensions impact on the third (from Florian 2008)

A useful addition to Florian's (Rouse's) model for teacher development might be to add the social dimension learning, so that the teacher is not alone but part of a social learning system, learning with and through connection with other teachers so that 'knowing', 'beliefs' and 'doing' (let's call them 'knowledge, values and practice') are shared within the community, giving rise to a fruitful development of knowledge and practice through the growth of shared understanding. Allan's (2008) notion of 'interstanding' is useful here. Allan proposes the word 'interstanding' as the seeking for meaning and shared understanding, suggesting a dialectic approach rather than a fixed position and hints at, as I understand it, the fertile space that lies between seeking and finding. Like Florian, Allan offers a way of thinking about professional development that links knowledge acquisition and development of practice with values, a dimension that has perhaps been missing from the resources and packages of advice offered to teachers (Allan, 2008), but Allan's emphasis on the need for interstanding has the useful dimension of placing individuals, not alone and adrift, but in collaborative connection with colleagues. This is the kind of dynamic, collaborative approach to learning and harnessing knowledge that also belongs to the CoP model and I believe it offers a useful way of thinking about issues of

professional development that are implicit in my main research question<sup>11</sup>. I discuss CoP theory more fully in Chapter 5 where I show its impact on my research design. Slee (cited in Allan, 2008) argues that the building of community and social capital between teachers has the potential to reinvigorate the profession. This resonates with the call from Khaldi & Wahbeh (2002) for the empowerment and educational development that would ensue from collegial knowledge-sharing between Palestinian teachers. This is an interesting area of exploration for my research, for although the social bonds and sense of community may be there, as we have seen, the traditional passive model of learning (Jentoft, 2009; NAD, 2010; Wahbeh, 2011) may be uncondusive to peer-to-peer knowledge sharing of the CoP model.

This discussion on inclusion has now included thoughts about CoPs as a model for professional development for teachers. Inclusivity is also important within communities of practice. There is a danger that CoPs can become exclusive (Wenger et al., 2002) precluding the learning that diversity of membership can bring. In the domain of autism education it is essential to include diverse perspectives of all those who have a stake in the development of practice: parents, the wider community, practitioners, ancillary staff, researchers, specialists and, most importantly adults and students with autism. Enabling participation and listening to the voices of people with autism is important (Milton & Bracher, 2013), an interesting issue for my research as the literature suggests autistic voices are not heard in Palestine. CoPs can also operate across institutional, cultural and international boundaries, and interaction between communities is needed (Wenger, 2009) to ensure a balance between having regard for established practice and shaking free from it, possible when

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<sup>11</sup> Main research question: What opportunities can be found to develop inclusive educational practice in Palestine; with special reference to the developing practice in two schools?



communities interact and explore perspectives beyond their own boundaries (ibid). A plurality of perspectives offers fertile possibilities for inclusive research to include the less powerful (Booth & Ainscow,1998). Ballard (2003) argues that 'inclusion is about ourselves' and as well as the importance of inclusion for our children, teachers should be thinking of ourselves as a part of the communities we work in. In his chapter entitled 'Including ourselves', Ballard warns against the commodification of teaching, where the teacher's role has been reduced to managing learning outcomes for 'learners'. The CoP model, I suggest, offers a means of inclusion, belonging, and empowerment. More than this, it offers a model for knowledge sharing as an act of international citizenship.

### **3.5 Conclusions**

'Inclusion is never complete, but always in process' (Allan, 2000:43). For those who would work for a fairer and more equal society that offers the significant all-round social benefits that greater equality can bring (Wilkinson & Pickett 2010), inclusion is something to be worked at and puzzled over. In this chapter I have looked broadly at the issue of inclusion before, in the next chapter, thinking more specifically about autism. The literature about Palestine shows a belief in the importance of education, enthusiasm for an imprecise notion of inclusion but absence of thinking about educational practice for children with autism or how they might be included within educational provision. Drawing on the literature on inclusion I have focussed on a non-dogmatic approach that sees inclusion as a process that considers the needs of those who are to be included and pays heed to what we are including them into. I have discussed the lack of clarity in what we mean by 'inclusion' and a lack of research evidence to show us when it has been achieved. I also looked at the many

barriers to inclusion and the need to retain optimism and a sense of the growing impetus towards IE. I discussed the damaging impact of exporting approaches from 'developed' countries to less 'developed' regions of the world when cultural, historical and economic differences are not taken into account. I have drawn attention to the potential for harnessing knowledge and developing inclusive practice that can derive from the sharing of knowledge, practice and values between people, both locally and internationally, and I have discussed this through the perspective of CoPs. I have seen inclusion to be not just something we want for our children but something for ourselves. This has led me towards a model for professional development where, borrowing the notion of 'interstanding' from Allan (2008), knowledge acquisition and development of practice are linked with the exploration of values within a framework of social learning afforded by the CoP model, and I have found that this is an approach which is in tune with some current thinking in Palestine about teacher empowerment and educational development (Wahbeh, 2011). The inclusion project is a conundrum and 'we must continue to puzzle over it together with those who stand to gain most' (Allan, 2008:164). Among those who stand to gain the most are perhaps children with autism and in the following chapter I look for contributions to the puzzle of IE from thinkers, both autistic and non-autistic, in the literature on autism education.

## **CHAPTER 4: AUTISM AND EDUCATION: A REVIEW OF THE LITERATURE**

### **4.1 The concept of autism**

Fundamental to thinking about education for autistic children is our concept of autism. In the sixty or so years since autism was described, independently and in different continents by Leo Kanner (1943) and Hans Asperger (1944) our understanding of autism has evolved. Autism is now widely seen as a lifelong, neuro-developmental condition that gives rise to difficulty with flexible thinking and with understanding other people and social situations (American Psychiatric Association, 2013; World Health Organisation, 1992). This can give rise to social and behavioural differences such as restricted interests, literal thinking and failure to develop age-appropriate peer relationships, (World Health Organisation, 1992). The term 'autism spectrum' was introduced by Wing (1996) giving us the concept of a broad spectrum encompassing a wide range of abilities and differences, and it includes sub-categories such as classic autism, Asperger syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS), all of which have a shared set of common features which Wing called the 'triad of impairments': social interaction, social communication and social imagination, further refined by Jordan (1999). As well as these three broad domains, it is now recognised that there are frequently sensory atypicalities in the way that a person with autism relates to the environment, acknowledged in the latest revision of the Diagnostic and Statistical Manual, DSM-V, (American Psychiatric Association, 2013). Sensory perceptual differences of people with autism may include hypersensitivity, hyposensitivity, fragmented and distorted perception, delayed perception and sensory overload and may account for the many difficulties that they experience (Bogdashina, 2004), with important implications for

teachers and practitioners. Differences within the domains of social interaction and communication, now merged in the recent amendment of DSM-V (American Psychiatric Association, 2013) to become 'social communication', can cause profound and wide-ranging difficulties in relating to other people and a loss of the opportunities for social learning that are available to typically developing children. There is a 'biologically based failure to recognise social and emotional signals' (Jordan, 2002) and the difficulties stemming from this affect learning and social and emotional development. When this is not understood it can result in thinking of the child as difficult, naughty or unteachable.

Intellectual disability occurs in about half of young people with autism (NICE, 2013). Also there is often a gap between cognitive abilities and daily life skills such as getting dressed, making it more difficult to function in everyday life (Charman et al., 2011). Language disorders are common and autism is the only condition where language and communication take separate developmental pathways (Jordan, 2002), so that a child with apparently good language skills may have significant difficulties with inter-personal communication. Poor coordination, clumsiness and unusual gait are also often features of autism (NICE, 2013). Many of the characteristics of autism that can present difficulties are found to decrease as the child develops (ibid). The diversity of ability within autism is huge and some people with autism can have extremely good abilities to absorb and process information and, as adults, can thrive in working environments which suit them (Motttron, 2011). A minority of people with autism have truly exceptional skills and are sometimes known as 'autistic savants'. Stephen Wiltshire, for example, makes detailed drawings of urban landscapes from memory after one viewing (Wiltshire, 2013); Daniel Tammet (2007) mastered the

Icelandic language in one week and has a unique ability with numbers enabling him to recite the mathematical constant for Pi from memory to 22,214 decimal places. Stories like these hit the news headlines, but exceptional savant skills are not common.

On-going revisions of the way in which autism is conceptualised and described have taken into account new insights, research findings and sensitivities towards the place of people with autism in society, with significant contributions from people who are themselves on the autism spectrum (Grandin, 1995; Milton, 2014; Mukopadhyay, 2011; Nazeer, 2010; Sainsbury, 2000; Williams, 1999). People with autism do not want to be seen as tragic figures (Sinclair, 1993) and have helped increase awareness of strengths as well as difficulties associated with autism. Recognition of strengths and of the strong interests that a child with autism might have, offer a better way to work with autistic children (Happe, 2001), although that is not to deny the significant difficulties that will affect learning and behaviour for the child with autism (Charman, et al., 2011). It matters how we think about disability or differences. The medical model or deficit model of disability locates difficulties within the child and considers how to 'treat' or 'cure' the child (Rieser & Mason, 1990), or change the child so that he fits in. Against this, the social model of disability holds the view that problems that arise are the result of our failure to provide an appropriate and enabling environment. Increasingly, many people with autism speak against the medical model which would see them as defective and in need of fixing (O'Neill, 1999). Jackson, a young man with autism, compared looking for a cure for autism with Hitler trying to create an Aryan race (Jackson, 2002). Sainsbury (2000) laments that 'the impulse of teachers is to try to make autistic children be 'normal' at the

expense of actually educating the child' (p.34). Speaking for the increasingly vocal neurodiversity movement, Stanton (2013) vehemently opposes the medical model which pathologises autism, saying instead that autism is a natural human variation rather than a disease and that autistic people need to be understood, not 'cured'. Silberman (2015) also reframes autism and, applauding the work of autistic self-advocates, offers a celebration of diversity. Beardon & Edmonds (2007) assert that NTs (neurotypicals) have a lot to learn from Aspies (people with Asperger syndrome). Social acceptance of diversity varies from culture to culture (Dyches et al., 2004; Feinstein, 2010; Grinker, 2009; Kim, 2012). In English the word 'diversity' has positive connotations whereas in Korea, for example, society places high value on sameness and seeks blame for difference (Grinker, 2009). Mottron (2011) argues that the hallmark of an enlightened society is the inclusion of people with differences and that people with autism can make extremely valuable contributions to society, for instance in the field of scientific research.

#### **4.2 Identification of autism**

It is believed that autism has existed throughout history (Frith, 2003). In the UK autism is said to affect one person in a hundred (Baird et al., 2006), with perhaps four boys for every girl with autism, and it is more likely that an individual with autism will have relatives who have autism. In the face of an apparent increase in the number of people with autism, Grinker (2009) dismisses the idea of an autism epidemic, saying there are a number of factors behind the increase of diagnosed cases: better, earlier and more accurate diagnosis; a broader concept of autism allowing for more cases at opposite ends of the spectrum; a recognition that many people with other diagnosed conditions also have autism; and improved methods for collecting epidemiological

data. However, the possibility of a real increase in autism cannot be ruled out (NICE, 2013).

The question of whether autism is equally prevalent in all societies is pertinent to this study, although the evidence is inconclusive. Dababnah (2013) found few studies relating to prevalence in the Middle East and none in the West Bank where she researched the experience of parents of children with autism. It is believed by some that autism knows no geographical, cultural or racial boundaries (Feinstein, 2010) although this has not always been the view and early autism theories saw it as being bound by culture. For example, Sanua (1984, cited in Feinstein, 2010) saw autism as 'an illness (sic) of western civilisation' (p.65), which 'appears in countries of high technology, where the nuclear family dominates'. More recently, however, Daley (2002), calling for more cross-cultural research into conditions such as autism, felt that it was safest, in the absence of data, to see autism as a universal phenomenon which occurs in all cultures. An epidemiological study (Fombonne et al., 2001, cited in Dyches, 2004) found no evidence for differences in ethnicity regarding pervasive developmental disorders including autism. However Hassan (2012) found a far higher prevalence of autism in Somali, black African and black Caribbean children in one borough in the USA. Ben-Sasson (2012), in a study in Israel, adopts the working hypothesis that autism rates are stable across cultures and in this he concurs with Daley (2002). Both Ben-Sasson (ibid) and Matson (2011) before him looked at how cultural perceptions relating to typical behaviours and normal development could impact on diagnosis and the implications of this for screening, for behaviours that are markers of autism in one culture may not be viewed as abnormal in other cultures (Kim, 2010). Indeed, autism might manifest itself differently in different countries

(Matson, 2011). There are no final conclusions to be drawn here in terms of prevalence rates across the world. However, the evidence does not support differences in autism prevalence by geographic region and neither does it suggest a strong impact of ethnic/cultural or socioeconomic factors (Elsabbagh et al., 2012). This is an area where further knowledge would be useful.

In many parts of the world a multi-agency approach, involving parents is recommended for the process of identification and intervention (NIASA, 2003). Some forms of autism can be diagnosed by the time the child is two but often it is later. One study (Popovich, 2013) holds out hope for the possibility of diagnosis as young as nine months through the use of eye tracking technology to identify gaze patterns. Adults are sometimes diagnosed as autistic after years of struggling with a sense of not fitting in socially. Diagnosis is seen by some autistic people as a useful signpost to point educators in the right direction when thinking about the child's needs (Blackburn, 2000; Lawson, 2000; Sainsbury, 2000; Williams, 1999;). However, diagnosis is not a predictor of educational needs as no two children with autism are the same; education should therefore be needs-led not diagnosis-led (DfES, 2002; NIASA, 2003) although diagnosis can be a useful guide. In the absence of reliable diagnosis, as in Palestine (Zayed & Banifadel, 2012), there are still opportunities for the teacher or practitioner with awareness of autism and a willingness try to understand the child to use approaches that will help a child with complex communication difficulties, and working with an undiagnosed child as if they have autism will not harm them (Jordan, 2002).



### **4.3 Autism and education**

The writing of autistic people is instructive of how appropriate approaches make a difference for pupils who might otherwise not succeed or cope in the school environment (Grandin, 1995; Nazeer, 2010; Sainsbury, 2000; Williams, 1999 ). Tito Mukhopadhyay, a young, non-verbal man with autism, writes forcefully about the importance of education and laments the time wasted searching for ‘cures’ when he was little (Mukopadhyay, 2011). However meeting the needs of children with autism in schools is not straightforward, and when it goes wrong they can experience bullying, isolation and rejection (Jackson, 2002; O'Neill, 1999; Saperstein, 2010) and are at risk of exclusion from school (Batten et al., 2006). Interventions and so-called ‘cures’ for autism are commercially available in bewildering numbers sometimes leading parents down costly blind avenues. Many interventions are unsupported by evidence (Fleming et al., 2015; Research Autism, 2015) and some are hazardous and contrary to medical guidelines (NICE, 2013). Fitzpatrick (2009), a family doctor with many years of experience and a son with autism, gives a damning critique of the many biomedical approaches lacking scientific rigour that are on offer to vulnerable parents. My thesis supports the view that education is of fundamental importance for people with autism (Parsons et al., 2009; Baron-Cohen, 2008) and I now look at some of the principles to guide educational practice. The literature I draw on is mainly from writers in the UK, with some from the US, and reflects my own ethos, values and understandings.

### **4.4 The need for understanding**

The need for understanding is crucial for inclusion of children with autism, but it is a condition that can be difficult to comprehend. By tying a scarf round our eyes, we can

begin to think what it must be like to be blind but it is not so straightforward for neuro-typical people to relate to the social blindness of autism. As Peeters & Gillberg (1999:90) put it: 'we do not understand what it means with our heart or our guts'. This inability of educators to truly relate to what it is like to have autism has led to some lamentable experiences of misery in mainstream education, as people with autism have told us (Jackson, 2002; O'Neill, 1999; Sainsbury, 2000; Williams, 1999). Teachers, practitioners and all who come into contact with the child with autism need an understanding of the condition (Jordan & Powell, 1995) as approaches to working successfully with autistic children are often counter-intuitive. For instance, children with autism are often asocial learners, whereas teachers often teach in a way that is social (Powell, 2000), and praise is often meaningless and distracting for the young child with autism (Jordan, 2002). 'Amor NON vincit omnia'<sup>12</sup> is a caveat offered by Peeters & Jordan (2010) who alert us that we need to be willing to adapt our natural style of communication and social interaction when working with children with autism.

As well as the need to understand autism it is also important to understand the individual child, his strengths, difficulties, interests and the way in which his autism affects him (Jordan, 2002; Prizant & Whetherby, 2006; Jordan & Powell, 1995) as autistic children often have an uneven profile of development. A high level of ability in one area may be set against low ability in another. Sainsbury (2000), for instance, gained a PhD in Politics and Philosophy from Oxford but did not master crossing the road or buying from a shop until in her late teens. The SCERTS<sup>13</sup> Model (Prizant & Whetherby, 2006) offers a framework for determining the child's individual profile and developmental level, and choosing appropriate interventions. The model is complex

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<sup>12</sup> Love does not conquer all (i.e. love alone is not enough)

<sup>13</sup> Social Communication, Emotional Resilience and Transactional Support

and exacting, yet it is based on research evidence and there is much that can be borrowed from it, as indeed I do in the action research dimension of my study, especially the importance it attaches to observation and understanding of the individual child, their strengths and interests as well as their difficulties. Autism is a transactional condition that challenges intuitive assumptions (Jordan, 2005) and lack of understanding can lead to misinterpretation of the behaviours of autistic children and compound the problems in kindergarten or in school. 'Challenging behaviour is best seen as a form of communication' (Jones et al., 2008:16) as it can be the result of social confusion, anxiety, communication difficulties, sensory difficulties or rigidity. Rather than perceiving behaviour as difficult or naughty, it can be usefully viewed as having a function that we can seek to understand (Prizant & Whetherby, 2006; Cumine et al., 2010) in order to support the child to develop better coping strategies and stronger emotional resilience. If children with autism are to be included in education, teachers, parents and practitioners require understanding, knowledge and skills in order to be effective (Guldberg et al., 2011). Given this, my research considers what kind of model of professional development might be appropriate in Palestine, and valued by the people that it is aimed at (Charman et al., 2011; Jones et al., 2008) as well as taking into account existing opportunities.

#### **4.5 The need for an enabling environment**

We bear a responsibility to provide an environment that is beneficial (Jones et al., 2008), and rather than blaming the child if he is unable to cope in the setting that we put him in, we must change the environment, not the child (Jones, 2002). For instance, sensory differences experienced by children with autism hold the potential for sensory overload and heightened levels of anxiety and stress (Bogdashina, 2004)

and must be considered. Training materials developed by the Autism Centre for Education and Research (ACER, 2013) give useful guidance on the many ways in which schools can modify and structure the environment for children with autism. It is necessary to go beyond just thinking about the physical environment to think about how we work with the child with autism including how we adapt our language, communication and style of interaction (Guldborg, 2010) and the characteristics that we as teachers and practitioners bring to our role (Charman et al., 2011; Jones et al., 2008; Peeters & Jordan, 2010). Writing as an adult with autism, Sainsbury (2000:100) talks of a need for teachers to 'demonstrate an active willingness to learn' and 'try new things and think outside the box' and there is a growing recognition of the need to consult and involve people with autism on these issues (Pellicano et al., 2014).

#### **4.6 The need for collaboration**

In the UK we have come a long way from the days when 'refrigerator mothers' were blamed for their children's autism (Bettleheim, 1967). Now, parents and families are more usually seen to be the 'experts' who know their children best and are valuable partners who can work together with the professionals to meet the needs of the child with autism (Charman et al., 2011; Hesmondhalgh, 2006; Prizant & Whetherby, 2006). There is recognition of the need to support families who have children with autism (Charman et al., 2011; Jones et al., 2008), taking into account the perspectives of all family members (Preece, 2014). There is a strong imperative for agencies to work together to support the child with autism (Parsons et al., 2009; Charman et al., 2011) and indeed for staff within schools to have a shared understanding of best practice; there is also a need for skills to be shared between

professional disciplines (Jones et al., 2008). A raising of awareness of neurodiversity is needed amongst the school community as a whole, including peers and ancillary staff and also in the wider community (Charman et al., 2011). Collaboration must also include the child, whose voice is important so that we listen and hear the child's views (Charman et al., 2011; Jones, 2008; Parsons et al., 2009), a key factor in ensuring successful inclusion for children with autism (Hesmondhalgh, 2006). Autistic adults are themselves crucially important collaborative partners, increasingly so, in the guiding of policy and planning (Guldborg et al., 2011; Milton, 2014; Pellicano et al., 2014; Wittemeyer et al., 2011).

#### **4.7 Autism and inclusion**

Children with autism can benefit from learning alongside their peers (Jordan, 1999; Guldborg et al., 2011,) perhaps also to the benefit of other pupils and staff (Jordan, 2008). Literature from the field of autism, stresses the importance of community and the cultural milieu of schools as a key factor in enabling inclusion (Jordan, 2008; Guldborg et al., 2010; Parsons et al., 2010; Kasari & Smith, 2014; Autism Education Trust, 2013) and this view is strongly reflected in the wider literature on inclusion (Cummings et al., 2004; Booth & Ainscow, 2011; Nes, 2003; Thomas & Loxley, 2001; Thomas, 2013b). However, because of the complex social difficulties in autism and the challenges that children with autism can have in negotiating the social environment of school, the autism literature is perhaps more nuanced, flexible and concerned with process than that of some of the previously mentioned writers on inclusion. For example, Jones et al. (2008) offer a definition of inclusion that includes the following: 'School inclusion is the process of including and educating a pupil within a school (*mainstream or special*), where the school is able to recognise and

assess the pupil's particular needs .....’ (my italics). In this definition, segregation is not the binary opposite of inclusion; ‘special’ can also mean inclusion. Guldberg (2010), thinking about the pre-conditions that would support inclusion, sees inclusion as ‘the process of identifying, understanding and breaking down barriers to participation and belonging’ (p.168). Again, the emphasis is on the process of supporting participation. It seems that there may be a consensus among those who have focussed their work on the education of children with autism that a variety of forms of provision may be needed and that, for a few children with autism, inclusion alongside their neuro-typical peers may be too difficult to achieve (Hesmondhalgh 2006; Jordan, 2008; Parsons et al. 2009; Wittemeyer et al., 2011 ). My experience leads me to align myself with this position, while working to achieve the conditions necessary for full inclusion. Special provision can have a place within an inclusive system of provision. However, as Jordan (2008) argues, special schools must have a better reason for their existence than as a dumping point for those who have failed in mainstream. Jordan (ibid) suggests that specialist autism schools could and should be pioneering centres of excellent practice, linked to research and providing outreach support for mainstream inclusion. This is a model that could perhaps fit well with conditions in Palestine as progress is made towards developing inclusive practice within mainstream schools.

For children with autism, and indeed for all children, IE is about good education (Florian, 2008; Ballard, 2003) and the important question is: what are we including the child into? If it is into a situation which does not meet their needs then this is not inclusion but an unhelpful form of integration (Jordan, 2008), and many of the researchers in the field of autism education have focussed primarily on the ‘how’ of

inclusion for children with autism (Charman et al., 2011; Guldberg, 2010; Jones et al., 2008; Kasari & Smith, 2013; Parsons et al., 2009 ). Inclusion is founded on a belief that people are entitled to be different so it makes no sense to talk of including a child with autism, or any child for that matter, into a school that is not able to meet their needs; this might be integration, but not inclusion. For a child to be included there needs to be participation and belonging. It is the quality of IE that has to be confronted (Corbett, 2000) and we must counterbalance the arguments that unreservedly support inclusion into mainstream (ibid). A useful counterbalance is to be heard in the voices of people with autism who tell us not only about the importance of good education and good teachers (Grandin 1995), but also about the dangers inherent in so-called 'inclusion' (Jackson 2002; Sainsbury 2000; O'Neill 1999). Sainsbury (2000) questions the 'dogma' of inclusion and explains how overwhelming and challenging the mainstream school can be for many children with autism. Children with autism can experience significantly higher levels of social rejection and bullying (Symes & Humphrey, 2010; Humphrey, 2008; Jackson, 2002; O'Neill, 1999), as indeed can other children with special needs (Norwich & Kelly, 2004), and so we need to be cautious. In the UK 70% of children with autism are educated in mainstream schools (Charman et al., 2011), but there is still a significant proportion of children with autism who are included within the education system but not in mainstream schools. A range of provision is needed (Jordan, 2008; Wittemeyer, et al., 2011) and no single type of educational placement can meet the needs of all (Parsons et al., 2009; Hesmondhalgh, 2006).

#### 4.8 Some implications for my study

Chapter 2 drew attention to the scarcity of autism-related literature in Palestine, coinciding with testimony from those in Palestine who urged me to undertake this study and told me of the lack of knowledge about autism. This, together with the lack of clarity about inclusion in Palestine, discussed in the previous chapter, and the fact that Palestine is not a wealthy country, led me to reflect on how my understanding of IE for children with autism might relate to the Palestinian context, the main focus of my research question. This chapter closes with a drawing together of findings from the three chapters of my literature review. Table 2 highlights factors in Palestine that are at variance with some frontline features in the thinking that has underpinned international developments in educational inclusion for children with autism: the empowerment of parents of autistic children and recognition of their importance; understanding of autism as a neurological condition with a broad spectrum of strengths as well as challenges; professional development to enable teachers to improve practice; an understanding of inclusion that is about inclusive approaches to teaching and learning, valuing all children and breaking down barriers; a move away from medical and deficit models of autism; listening to autistic voices, including children's; coordinated policies and collaborative multi-disciplinary approaches. The synthesis in Table 2 presages some of the key issues that the research explores.

Issue	Synthesis of findings from the literature
1. Parents	Whereas parents are seen as the real 'experts' and valuable partners in teaching and supporting autistic children (Jones, 2002; NIASA, 2003; Charman et al., Prizant and Whetherby, 2006; Hesmondhalgh, 2006), in Palestine parents of autistic children are sometimes stigmatised and isolated



	(Dababnah & Parish, 2013). However, a study by Zayed and Banifadel (2012) acknowledges the critical role of parents and finds that many institutions in the community do value role of parents.
2. Diagnosis	Acceptance and understanding of the child's needs are perhaps more important than a diagnostic label (Kim, 2012; DfES, 2002; NIASA 2003), but diagnosis is thought to be important for enabling understanding and for getting appropriate support by many autistic people (Sainsbury, 2000; Lawson, 2000; Williams, 1999; Blackburn, 2000) and by professionals (Attwood, 2007). In Palestine, limited identification of SEN (Goldman et al., 2005), and, more specifically, of autism (Zayed & Banifadel, 2012), suggests that this is not available there for autistic children.
3. Attitude towards disability	A medical model of disability is unhelpful as it leads us to see the person with autism as defective (Rieser & Mason, 1990; O'Neill, 1999, Jackson, 2002; Stanton, 2013); and a charitable approach is not adequate (Peeters & Jordan, 2010) as we need to understand the autistic child. However, in Palestine charitable or medical models of disability and SEN are sometimes held. (Zayed, 2009; NAD, 2010).
4. Education and autism	Education is very important for children with autism (Baron-Cohen, 2011; Jones et al., 2008) and autistic children need to learn through and with other children (Jordan, 1999; Guldborg, 2010; Guldborg et al., 2011). In Palestine, however, children with autism sometimes remain isolated (Dababnah & Parish, 2013), and some children with disabilities miss out on education (Farrell, 2007). Lifshitz et al. (2004) found that children with disabilities were seen as incapable of development and needing medical care rather than education.
5. Inclusion	Palestine signed the Salamanca agreement on educational inclusion (UNESCO, 1994) and the UNESCO Education for All initiative in 2006. Palestinian law enshrines the right of children with disabilities to an appropriate education (Palestinian Authority 1999). Inclusion is about breaking down barriers to participation (Guldborg, 2010). In Palestine educators may need to be better informed about inclusion and understand that it is about overcoming barriers (Farrell, 2007). Moreover, although inclusivity can be promoted in schools and communities by creating environments that promote self-worth (Thomas, 2013), people with disabilities in Palestine are sometimes stigmatised and excluded (Zayed, 2014), as are children with autism (Dababnah & Parish, 2013).
6. Understanding autism	Whereas the literature shows that autism needs to be understood in order to teach and support the autistic child (Jordan & Powell, 1995), autism is not generally well understood in Palestine (Dababnah & Parish, 2013; Zayed & Banifadel, 2012).
7. Pedagogy	Approaches to teaching are important for inclusion and teachers need to be flexible and adapt to meet the changing needs of the child with autism (Powell & Jordan, 1997). They 'cannot rely on centrally determined curricula and teaching methods' (Jordan, 2008:13) and an eclectic stance is necessary (Jordan, 2002). However, literature describes Palestinian pedagogy as often didactic and rigid (Khaldi & Wahbeh, 2002; Farrell, 2007; Al-Ramahi & Davies, 2002; Karlsson, 2004) and notions of student-centred approaches may not be understood (Khalili, 2010).
8. Training of	Training is an important priority as practitioners and parents need specialist knowledge to understand inclusive approaches for children with autism

teachers	(Guldborg et al., 2011). In Palestine, however, there is need for training for teachers and practitioners in autism. (Zayad & Banifadel, 2012) and possibly better SEN training generally (Opdal, 2001).
9. Collaboration	For successful autism practice, skills need to be shared between professional disciplines (Jones et al., 2008), and understanding should be shared within in the school community and in the wider community (Charman et al., 2011). This sharing of practice is not customary in Palestine and there is scope for better opportunities for dialogue and collaboration amongst educators (Van Dyke & Randall, 2002; Wahbeh, 2011).
10. The child's voice	It is important to listen to the voice of the child (Parsons et al., 2009; Charman et al., 2011; Guldborg et al., 2011; Milton & Bracher, 2013). People with disabilities need to be given a voice in Palestine (Zayed, 2014), and a recent advocacy project in the West Bank (Burton et al., 2013) offers a new model of participation and empowerment.
11. The autistic voice	Autistic voices have powerfully helped us to understand autism (Grandin, 1995; Williams, 1999; Nazeer, 2010; Mukopadhyay, 2011; Sainsbury, 2000; Jackson, 2002; Milton, 2013). My literature searches suggested that those voices are yet to be heard in Palestine.
12. Coordination	There needs to be coordination between different government and non-government agencies in addressing the needs of children with autism (Parsons et al., 2009; Charman et al., 2011; Guldborg et al., 2010; NIASA, 2003); Zayad & Banifadel (2012) point to a need for greater government involvement in autism in Palestine.

Table 2: synthesis of findings from the literature

These three chapters have reviewed the literature that guides me as I embark on the search for answers to my research questions. The next chapter describes my research design.

## CHAPTER 5: RESEARCH DESIGN



Figure 7: Palestinian embroidery

Palestinian embroidery, a centuries-old tradition of cross-stitch, almost destroyed by the Nakba but now revived, has a wealth of intricate, meaningful motifs, added to over time by craftswomen, using individual and regional embellishments to produce clothing and household furnishings. The designs, vary with time and place, and have evocative names such as ‘moon of Ramallah’, ‘tree of scorpions’, ‘key of Hebron’. My research too tries to capture social meanings and unique, changing local perspectives as I bring together thoughts about Palestine, autism and IE, hopefully to offer something to be used. Perhaps the motif needed at the centre of my research design is one called ‘wide open eye’, to remind me of the researcher’s duty of open-mindedness.

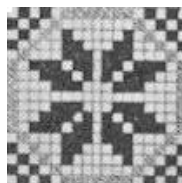


Figure 8: Motif: wide open eye

## **5.1 Introduction**

This chapter discusses my approaches and methodology with reference to the literature I consulted and shows how the approaches, the purpose, the questions and methods entwine. I worked with participants from two educational centres in Palestine to develop understanding and practice about educational inclusion of children with autism. Also I endeavoured to find out about approaches and perceptions towards inclusion and autism in the wider Palestinian context. The proper function of educational research is to inform policy makers and practitioners in order to improve education (Hammersley & Scarth, 1993) and my research is not a quest for knowledge for its own sake; it is about trying to make a contribution towards the inclusion into education for autistic children in Palestine. There are others in Palestine also working to develop practice in this field, both within the two participating schools and elsewhere. I worked in collaboration with these people where opportunities arose, and sought approaches that would enable me to explore perceptions, understandings and aspirations in a culture that was not my own.

## **5.2 Research Questions**

The preceding three chapters reviewed the literature relating to the key aspects of my research and helped me to refine the questions that shaped my research journey. Figure 9, revisits my sketch from Chapter 1 (Figure 2) where I used a Venn diagram to show the trichotomous nature of my research interests, and now illustrates how, in the intersections between the three main areas, lie the subsidiary questions for my research. It is here in the intersections that cross-cultural issues become important and point to the need for a broadly interpretative approach for my study.

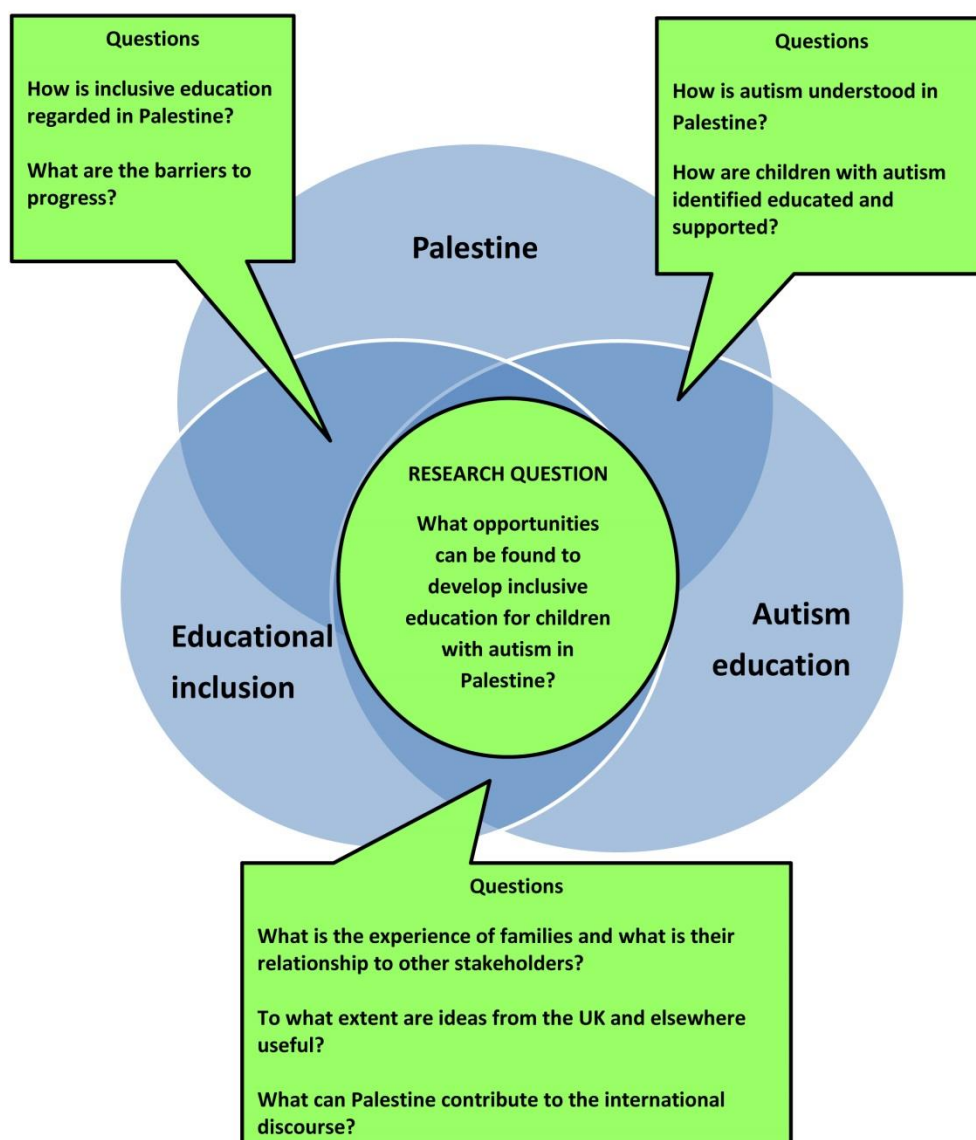


Figure 9: Research questions

Subsidiary questions are not limited to those shown in Figure 9, however, as each of these questions holds within it further questions and, like Russian dolls, within these questions yet more questions. An example of this is given in Figure 10. Many questions emerged during the course of my research. For example, before I embarked on my research I had not been aware of the great shortage of diagnostic capability for autism in Palestine and as this became apparent it led me to probe what this meant for families and educators. It also prompted me to ask questions

about the appropriateness and ethics of flagging up the issue of autism education and inclusion in another culture.

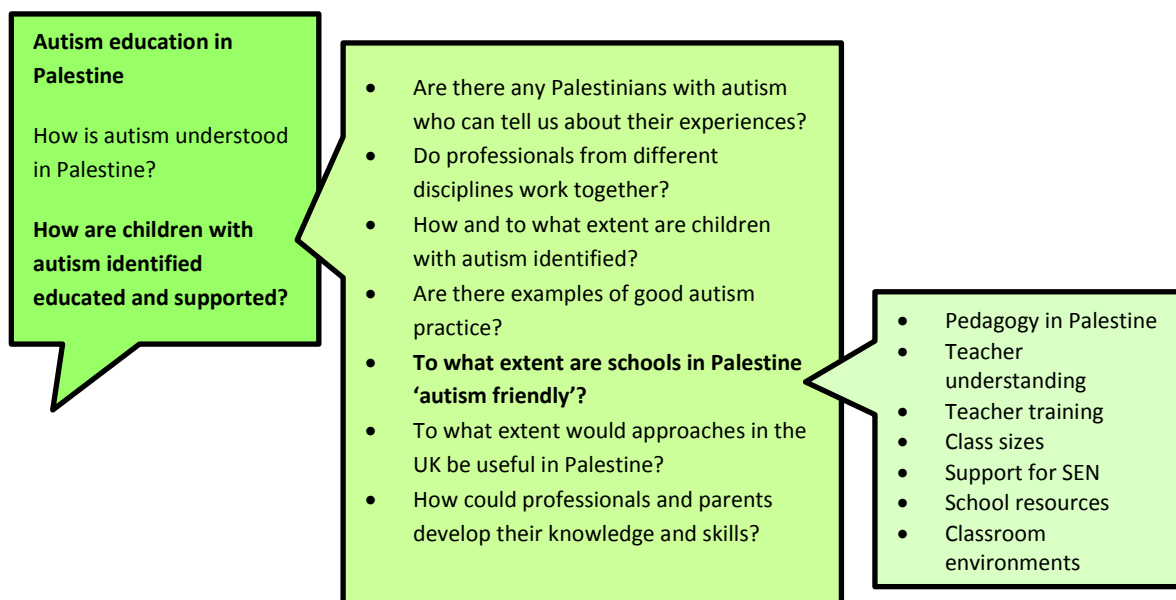


Figure 10. Each question holds further questions within it.

The expansive nature of my research and the on-going emergence of new questions had the potential to become an unwieldy search for answers to a never-ending list of questions. I had to set limitations and, for me, this was done by constantly referring back to the main research question, within which was embedded the original, very practical purpose of my research:

What opportunities can be found to develop inclusive education for children with autism in Palestine?

### 5.3 Research approach

My research questions strongly pointed to the need for a qualitative approach, being more about words, thoughts and impressions rather than quantities. A broad eclectic

approach was appropriate as I needed to find factual information about the existing situation as well as insights into opinions, attitudes, relationships and motivating forces. For example, in some instances I sought to obtain useful quantifiable information such as 'how many children with autism are there in this school?' or 'what is the size of classes?' More frequently though, I adopted flexible and open-ended approaches, seeking to understand other perspectives and, as Denscombe (2010) proposes, allow participants to 'develop ideas and speak more widely on the issues raised by the researcher' (p156). In yet other instances, I was like an historian eliciting accounts of how situations had developed, which helped my developing understanding of the circumstances. As the research progressed I saw other opportunities to develop my study, and so the term 'emergent design', although something of an oxymoron, describes the overall development of my study. I understand 'emergent design' to mean a flexible approach where decisions about methods can be taken at various stages of the research on the basis of contextual information. This delayed decision making was a positive aspect of the research process giving flexibility that would not have been possible if all the design decisions were taken at the outset (Burgess, 2006). This wish for a flexible, emergent-design approach, focussing on the unique and specific with the goal of understanding rather than predicting led me to choose an interpretative paradigm for my study.

#### **5.4 Interpretivism as a paradigm**

My task was complex as I was an outsider with perspectives and understandings about social relations, education, disability and difference that had been shaped by my own experience of living in the UK, a country very different from Palestine. My reading (Cross, 2003; Kisjani, 1998) had alerted me to the dangers of assuming that

what belongs to one culture can be imported to another. Not only that, but encouraged by Corbett (2000) and Thomas (2013b) I wanted to find what could be learnt by looking at the issue of inclusion of children with autism through the prism of Palestinian understandings. An interpretivist paradigm places importance on understanding meanings within social contexts and was chosen to enable me to explore meanings that the participants assigned to their experiences and delve into the social world of the teachers, professionals and families in Palestine. Rather than a detached, positivist paradigm, looking for scientific data that could be quantified and counted in order to prove or disprove a hypothesis, I opted for the more naturalistic and qualitative paradigm of interpretivism. An interpretative approach sits well with the idea that purely factual knowledge is hard to come by in the social sciences and that what we 'know' is constructed by us as individuals from our own standpoints. Rather than looking for mere 'respondents' to my questions, I was looking for an interactive approach and the involvement of 'participants' so that meaning-making could be a more collaborative, shared endeavour.

Interpretivism is open to attack for being unscientific, lacking in objectivity, producing findings that are ungeneralisable but I am persuaded by Thomas's (2009) side-stepping response to this criticism when he talks about the 'humility of interpretative research' (p. 77) in that it makes no grand claims about generalisability. Rather, its strength is in finding ways to deeper understanding of social situations. As Mack (2010) points out, a strength of interpretivism is that its goal is 'the creation of local theories for practice rather than generalizable findings' (p8) and she defends interpretivism as being an approach that problematizes and addresses issues productively. This was important for me in relation to the purpose of my research –



that it should be useful. Another criticism of interpretivism is that it is reliant on the researcher's own subjective interpretation of the data; in other words, my own interests, background and beliefs would get in the way of objectivity. I recognised that this placed on me, the researcher, a duty of 'balance, fairness and thoroughness' (Thomas, 2009) and so in my collection, analysis and interpretation of data, I recognised the need for rigour and striving for honesty.

In thinking about the problem of subjectivity in an interpretative approach it was useful to draw on interpretative phenomenological analysis (IPA). An important aspect of IPA is its focus on hermeneutics in interpretative enquiry, highlighting that as human beings we are all trying to make sense of our worlds, researcher and participants alike. IPA recognises there is a double hermeneutic (Smith et al, 2009; Smith & Osborn, 2008) whereby the researcher seeks to understand the participant's perceptions as they, the participants, are trying to make sense of their own perceptions. The researcher's access to the insider perspective is through the participant's account and so will be partial and subjective. This is further complicated by the researcher's own perceptions. My interpretations of the participants' accounts would unavoidably be filtered through the lens of my own perceptions. For example my understanding of autism had given me a positive attitude towards autistic people, a recognition of their rights to inclusion in education and in society and ideas about autism practice and this would affect my interpretation of the participant's contribution. There is a tension between wanting to take an insider view and wanting to question and think about it from a different angle. Smith et al. (2009) describe this in terms of an 'empathic hermeneutic' (trying to stand in the shoes of the participant) and a 'questioning hermeneutic' (keeping on one of one's own shoes, perhaps) that

wants to analyse and probe. My research approach was influenced by a wish to empower the participants by positioning myself as an ally rather than an authority, but at the same time my own conceptions were necessary to try to make sense of their world (Smith & Osborne, 2009) and so I was employing a double hermeneutic. Where I found IPA especially useful was in the design, conduct and analysis of the semi-structured interviews, discussed more fully below. Here I found that by positioning myself as curious, supportive and enabling, and seeing the interviewees as 'the experiential experts on the subject' (Smith & Osborne, 2008:59), the close one-to-one interaction allowed the possibility of personally salient accounts from the interviewees and provided data in the form of detailed verbatim scripts which could then be analysed. My awareness of the double hermeneutic was a valuable aspect of this process, enabling me to be conscious of being both inside and outside the worlds of the participants.

However, my research diverged significantly from the IPA framework in several respects. Although some of my subsidiary research questions were essentially about exploring perceptions, others were about practice. Also, as I sought understandings that would enable me to make recommendations about practice, my main research question was goal focussed, in a way that is not a feature of true IPA studies (Smith et al., 2009). Another departure from IPA tenets was in terms of breadth, as IPA studies tend to be conducted on small sample sizes (Smith & Osborne, 2009) to allow for very close attention to detail whereas my study required a much broader sample for the inclusion of multiple perspectives. Before I move on to write more about approach and methods, I discuss another theoretical cornerstone of my research, Communities of Practice.

## 5.5 Communities of Practice

I previously discussed (p.50-52) the potential merits of the CoP model for knowledge-sharing to harness and build on existing practice through partnership and peer-to-peer learning and, in the chapter on inclusion, considered this in relation to teacher development in Palestine, where the system ‘negates [teachers’] ability and capacity to organise themselves in communities of practice and learning to enhance their own teaching and engagement with education’ (Wahbeh, 2011:14), and where rote learning and didacticism are the main models for learning (NAD, 2010; Wahbeh, 2011; Jentoft, 2009). Before showing how my research design was influenced by CoP theory, it is useful to outline my understanding of CoP theory and explain why it was a useful dimension of my research.

In education, CoPs are increasingly used for professional development and offer a fresh perspective and new dynamism for learning (Wenger, 2009). The literature on CoP is rooted in social theories of learning whereby human learning and the development of knowledge is seen to be essentially social. This approach theorises learning as a cognitive process that takes place in a social context (Bandura, 1977), and through social interaction whereby learners are integrated into a knowledge community so that knowledge is constructed in collaboration with others (Vygotsky, 1978). Lave (1988) developed the notion of ‘situated learning’ and saw learning as situated, or embedded, in context and culture and similarly dependent on social interaction. In CoPs this learning comes about when ‘groups of people who share a concern, a set of problems or a passion about a topic’ ... ‘deepen their knowledge and expertise in this area by interacting on an ongoing basis’ (Wenger et al., 2002:4), and they are an ideal structure for stewarding the dynamic growth and development

of knowledge and practice (ibid). There is an ethical dimension to CoPs that challenges participants to see themselves as learning citizens contributing to the knowledge of the community (Wenger, 2009). Such a model could resonate well with the collectivism and shared Palestinians concern, described by Lifshitz (2004), for developing a strong society for the national good; and there is a suggestion (Wenger, et al., 2002) that CoPs might be easier to implement in more traditional societies where social bonds are tighter than they are in western countries.

In my endeavour to identify opportunities for the development of practice in relation to the inclusive education of children with autism in Palestine I found concepts from the literature on CoPs to be valuable. It offered a more egalitarian alternative to the hierarchical model of knowledge transmission from North to South or West to East, offering instead horizontal sharing of knowledge and practice within and between communities, placing value on connections between people to share, develop and harness knowledge and practice. CoPs can take varied forms in terms of size, duration, status; they can be geographically dispersed or co-located, homogeneous or heterogeneous, unrecognised or institutionalised. Within a community, participants share a strong interest about a 'domain' and Wenger (2009) describes how learning within the domain can be 'horizontal' or 'vertical'. Horizontal processes are to do with peer-to-peer sharing, personal identity, meaning making and being part of a community, whereas vertical processes include institutionalised expectations, prescribed standards and regulations. These are qualitative differences and Wenger went on to argue for the importance of 'transversal' linking of the horizontal and the vertical so that, importantly, knowledge could be shared at different levels across communities, for example between practitioners and policy makers. 'Practice' is

described as a 'mini-culture that binds a community together' (Wenger et al. 2002:39) and includes socially defined ways of doing things with shared approaches, standards, perspectives and values. The knowledge shared within the community can be both explicit and tacit and CoPs can become a means of eliciting valuable tacit knowledge (Guldberg et al., 2013).

Whilst there is potential for harnessing knowledge and developing practice within CoPs, it is important not to romanticise them (Wenger et al., 2002) as they also hold the potential for complacency and stagnation of ideas. This danger can best be avoided when CoPs interact with and explore other perspectives beyond their own boundaries (Wenger, 2009). It becomes 'a balancing act between honouring the history of the practice and shaking free from it' (ibid, p.3). So the boundaries between CoPs are important places where there is potential for new learning and development. Diversity within and between CoPs is an important element and makes for richer learning (Wenger et al., 2002). In a development of thinking about CoPs, Wenger et al. (2015) write in terms of a complex 'landscape' of practices, including groups of practitioners, but also researchers, teachers, managers, policy makers and associations. The term 'knowledgeability' (Wenger et al., 2015) is used to hold the idea of cross-boundary learning within a 'landscape of practice' across which individuals pursue their own trajectory of learning as they engage with or develop awareness of other CoPs and other perspectives. This social nature of learning and knowledge is a linking theme in my study and there is an interesting connection between CoP theory and the persuasive educational theory that sees autism as a transactional condition (Jordan, 2005; Prizant et al., 2006). In the latter, a basic tenet is that understanding the child's perspective, needs, wishes and developmental

status are fundamental to enabling development. Without understanding the transactional nature of autism there is a danger of misunderstanding the behaviour so that, for example, shouted demands become the naughtiness of a spoilt child, and our response is likely to be unhelpful. Learning and development depend on transactional processes that actively seek understanding of the other. Likewise, within and between CoPs, there needs to be exchange of ideas, a meeting of minds, a negotiation of meaning, for new learning to take place. There is an important dimension to this in thinking about communities of practice in the domain of autism education where the perspectives of people with autism are of fundamental importance (Parsons et al., 2009), and my research design sought to explore the potential for listening to autistic voices in Palestine. As the literature showed, in a region where people with autism and their families are stigmatised and socially isolated, this might be a new boundary to be crossed.

The potential rewards that can stem from 'boundary encounters' within a landscape of practice need to be planned for and are not easily constructed (Wenger et al., 2015). The literature offers useful case studies of how learning partnerships have been convened within complex landscapes of practice, (Cashman et al., 2015; Guldberg, 2010; Guldberg, in press) giving insights into the importance of careful planning. There is an important leadership role for those people who have the skills and understanding to forge new learning partnerships across the boundaries between CoPs. This role is variously termed 'systems convener' (Wenger et al., 2015), 'community co-ordinator' (Wenger et al., 2002), 'broker' (Wenger, 1998) and 'social artist' (Wenger, 2009). These insights into the shaping of CoPs, were influential in the design of my research and very important in thinking about my

findings and formulating answers to my research question. My research offered the opportunity to explore tentatively the 'pros and cons' of CoPs in a Palestinian context in several ways. Firstly, I worked with the participants of the focus groups (described below) in a way that sought to build on their existing practice and empower them through sharing knowledge, for example by developing a Wiki as a repository for shared knowledge, and by collecting and sharing 'stories' to describe practice. Secondly, hoping to exploit the important potential for learning opportunities in the boundaries between practices (Wenger et al., 2015) I planned to bring together the two groups of practitioners involved in the case study to explore how they might engage with each other productively and, hopefully, become part of a wider community of practice in the field of autism education. Thirdly, during the Study Day held at the end of the research period and discussed below, I took the opportunity to ask a diverse group of stakeholders what forms of collaboration were feasible for Palestine, which fed into the Recommendation 19 in my final chapter, concerning collaboration within a CoP.

Power and learning are inseparable, with competing voices and hierarchies of knowledge (Wenger, 2009), and my study recognises that the landscape of practice is political. Political structures regulate practice and knowledge and in Palestine this is made more complex by different regional accountabilities. While this study does not set out to look at these structures, it does seek for a better understanding of the opportunities, barriers and aspirations within the existing socio-political situation.

## **5.6 Contextual enquiry**

I call the first strand of my methodology a 'contextual enquiry' (Figure 1, p.6). This is not a formalised research strategy within the literature but it was an important, revelatory and substantial aspect of my research. By 'contextual enquiry' I mean that aspect of my research which seeks to understand the wider context within which my case study takes place and delves into the perspectives and realities of the people and institutions concerned with the education of children with autism within Palestine as a whole. My literature review gave me very limited access to this wider picture. The contextual enquiry was needed because a key purpose of my case study was to provide meaningful recommendations widely applicable within Palestine; this required better understanding of the wider context. For example, I needed to find out about policies, practices, attitudes and aspirations within the education system. Many of my research questions depended on this strand of my research so that I could explore perceptions of autism and of inclusion, approaches to identifying, educating and supporting autistic children, the barriers, and aspirations, the experience of families and their relationship to other stakeholders. This aspect of my research used the same interpretative approach as the case study, following a flexible and responsive, emergent approach whereby I elicited multiple perspectives by seeking out participants who had a stake in the research issues. Those who participated were parents, staff at the Ministry of Education, community providers in centres for children with special needs and autism, teachers, health professionals and staff at two universities. Table 3 gives an overview of the participants in the contextual enquiry. I conducted 19 semi-structured interviews and 11 or more informal discussions; I visited six centres of special needs provision within communities throughout the West



Bank; I held a two-day workshop for Inclusive Education Counsellors during which they took part in discussions and completed a questionnaire, giving me important access to a key group of professionals; and I had a final study day for participants and other interested parties which provided valuable data. Table 5 (p.99) gives a comprehensive overview of the data-collection methods and participants. There is some overlap between the participants in the two research strands, as for example where teachers or parents involved in the case study provided data that related more appropriately to the contextual enquiry.

Contextual Enquiry Participants		
	Number	Setting
Ministry of Education (MoEHE) officials	2	MoEHE, Ramallah
Inclusive Education Counsellors and advisors	40	MoEHE workshop
Teachers	6	Friends School, 3 Amira Basma School, 3
Parents	7	Friends School, 4 Amira Basma School, 3
Resource Room in a school	1	Faisal Hussein School
Inclusive Education Project	1	Terre des Hommes, Jerusalem
Centres of community provision	6	Annahda Women's Centre Star Mountain Centre, Surda Friends of Autistic Children Tulkarem Rehabilitation Centre Amira Basma Centre
Universities	2	Ahliya University, Bethlehem An-Najah University, Nablus
Health professionals	2	Occupational therapist, ABC Speech and Language therapist, ABC

Table 3: Contextual Enquiry participants

There was a strong interrelationship between the contextual enquiry, the macrocosm, and the second strand, the case study or microcosm which I discuss next. In

describing this interrelatedness it is useful to draw on the idea of the hermeneutic circle (Smith et al., 2009) whereby to understand the part you look at the whole and to understand the whole you look at the part. Delving into the wider background of my contextual enquiry gave me a broader picture that enriched my understanding of the perspectives of participants in the case study, whereas the narrower focus of the case study enabled me think about the lived realities of a specific situation that I could then relate back to the broader context. This process of understanding and analysing the interrelatedness between the two took place iteratively throughout the research period as I reflected on the data. The idea of a hermeneutic circle usefully conveys a non-linear way of thinking, but perhaps 'spiral', while keeping the sense of circularity, would better denote the movement and development of thinking that I experienced. The combination of using contextual enquiry and the case study enabled me to have a better understanding of the general, the macrocosm, delve into the particular, the microcosm and use the two to identify factors that contributed to successful outcomes and could be applicable on the larger scale.

## **5.7 The case study**

In the case study, the second strand of my study, I worked with teachers and practitioners as they strove to include children with autism in two schools in Palestine. I describe this strand of my research as a case study with a dimension of action research. The case study is a research strategy that investigates a naturally-occurring, contemporary phenomenon within its real-life context using multiple sources of evidence (Robson, 1993:52). Its aim is 'to illuminate the general by looking at the particular,' (Denscombe, 2010:53). I take this to mean that, in a case study, there are insights to be gained from looking at the individual case that can

have wider implications and, importantly, that would not have come to light through the use of a research strategy that tried to cover a large number of instances, such as a survey approach. Thomas (2011) describes the case study as a natural bedfellow of interpretative enquiry and a holistic way of analysing social phenomena. The case study also has strong links with a mixed-methods approach (Denscombe, 2010) and is able to contain a variety of different methods, all of which would be valuable for the triangulation of my data. One of the strengths of the case study approach, writes Robson (1993), is its flexibility and this suited my wish for an emergent design approach. This view was supported by both Thomas (2011) and Altricher & Feldman (1993) before him who wrote that there are no fixed methodological rules in the case study approach. In addition, Denscombe (2010) suggested that the case study approach was 'particularly suitable where the researcher had little or no control over events' as there would be 'no pressure to impose controls or change circumstances' (p.62). All these factors persuaded me that a case study would serve well as the framework together with, as I will show, an action research dimension. A recurring theme in the literature about case studies concerns the question of scientific validity (Denscombe, 2010; Stake, 2000; Thomas, 2011). I am persuaded that by conducting my case study in a manner that was responsible and responsive, reflective and rigorous, I was able to draw rich information and valuable insights. In this, I was encouraged by Thomas (2011) who claimed that case study as a research approach 'is science. In fact it is the essence of good science,' (p.23). A summary of the data obtained from the case study strand of my research is given in Table 4.

<b>Case Study Data</b>
<b>Initial whole staff questionnaires</b>
<b>Interviews with staff and with parents <sup>14</sup></b>
<b>Classroom observations (written record)</b>
<b>Minutes of meetings</b>
<b>Email correspondence with teachers, practitioners and parents</b>
<b>Evaluations of activities</b>
<b>Wiki – (including materials developed in response to needs)</b>
<b>Participants’ stories</b>
<b>Focus group interim questionnaires</b>
<b>Focus group final questionnaire</b>

Table 4: Data from the Case Study

The literature also talks of the holistic nature of the case study and in this respect my case study may not correspond to the reader’s expectations. Thomas (2011) writes that a case study approach, drawing on Gestalt psychology, ‘sees something in its completeness, looking at it from many angles’ (p.23), and Denscombe (2010) also describes the ‘holistic’ approach inherent in the case study. Limitations were necessarily imposed on my case study since it took place in another country, culture and language. This meant that in terms of ‘completeness’ my case study may not wholly fulfil expectations of a case study. However, both in terms of investigating a ‘naturally-occurring, contemporary phenomenon within its real-life context using multiple sources of evidence’ (Robson, 1993:52), and also in terms of aiming to

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<sup>14</sup> Data from the interviews has also been used to inform my contextual enquiry.

‘illuminate the general by looking at the particular’ (Denscombe, 2010:53), I believe the description of ‘case study’ is valid.

I will reflect on how I chose my cases. Cases are not selected randomly, as might be good practice for other research methods, but for known attributes (Denscombe, 2010), and the criteria for selection of cases needs to be made explicit. The criteria for my selection of two schools were:

1. The school would have, or at least wish to have at least one child considered to be on the autism spectrum
2. The school staff would want to participate in the research.
3. At least one of the schools would be a government school (ie. not a private school)
4. The schools would be geographically accessible within the West Bank and/or East Jerusalem (ie. not in Gaza)

My pre-existing relationship with Friends Girls School (now co-educational) in Ramallah made it an obvious choice for one of the schools and they were keen to participate. Friends Girls School is a private school which, unlike other schools in Palestine both private and public, has a policy and practice of inclusion for children with additional needs, and they had four children with diagnoses of autism. It felt important that I should balance this with a Ministry school as the second school. As it turned out, it was not possible to meet the third criterion for although the Ministry of Education supported this proposal and welcomed my research, it proved impossible to find a Ministry school that wished to participate. I was unable to establish whether my research seemed irrelevant, burdensome, threatening or whether I had just failed to explain the research in a way that enticed them. However, despite repeated attempts, this was not possible. The second school at the Amira Basma Centre in East Jerusalem was a choice that I initially resisted for although I had helpful

contacts there, admired their work and they were interested, it was also a private school, albeit of a very different kind. Compromises are sometimes necessary and it would be naïve to ignore the need for practical considerations in the choice of cases (Denscombe, 2010). As it transpired, Amira Basma Centre has been a very fruitful choice for my case study. Although it is private, fees are very small and the background of the children who go there is far from socially privileged. It adds significantly to the tapestry of my research and, with both schools, I am enormously grateful for their involvement and commitment. Neither of the two schools is typical of Palestinian schools and they are very different from each other although they are both leading the way in autism practice in Palestine. The comparisons and contrasts between them are an intriguing feature of my study; one of the happy features of the bringing together of these two schools within my study is that they each have different areas of developing expertise from which, potentially, the other can learn. The two settings are introduced more fully in Chapter 7.

Case studies can take many forms and serve different purposes (Thomas, 2011). My case study, which is exploratory and interpretative, is also diachronic in that it explored and interpreted a situation that was changing and developing over the two and a half years of my fieldwork. It is instrumental in that it is a purposeful endeavour to make a positive difference to the education of autistic children in Palestine through a process that is evaluative and explanatory, leading to the building of theory or, as Thomas (2011) prefers to call it an 'explanatory model' (p.112). My case study involves two cases and the literature offers many different terms to describe research which involves more than one case (Stake, 2000; Thomas, 2011; Yin, 2009). These include: 'multiple', 'collective', 'comparative', 'parallel', 'nested' and 'dual', none of

which seem quite right for my study which I prefer to call a 'paired case study' to convey both the number of schools and the hoped-for relationship between them during the research process. The term 'paired' draws attention to the collaborative partnership that would, hopefully, create synergy for new shared learning, as discussed above in the section on CoPs. The bringing together of these two schools would enable me to explore the question of how they might engage with each other productively and, by inference, how other teachers and practitioners might also become part of a wider CoP in the field of autism education. Another positive result of the choice of a case study approach was that the reflective and enquiring stance that it demands, as opposed to the didacticism that I had read about in the literature about Palestinian education (Al-Ramahi & Davies, 2002; Farrell, 2007; Karlsson, 2004; Khaldi & Wahbeh, 2002 ), might 'rub off' on the participants in their thinking about their practice.

The advantages of the case study approach were its flexibility, its holistic and interpretative approach and the possibility for unique insights drawn from rich data. Literature that I have consulted seeks to defend the case study from the charge of 'soft' or potentially sloppy research with no verifiable or generalizable outcomes (Denscombe, 2010; Hitchcock, 1995; Robson, 1993; Stake, 2000; Thomas, 2011; Yin, 2009). Denscombe's defence (2010) is that the extent to which the case can be generalised depends on how far the case study is similar to others of its type, and he characterises this in terms of physical location, historical location, social location and institutional location. Stake (2000) writes of 'naturalistic generalisations' (p.22) which, although they have not passed any scientific tests, he applauds and says are intuitive and empirical and develop within a person as the result of experience. Thomas

(2011), in discussing the difficulty of generalisation uses the terms 'abduction' and 'phronesis' which usefully seem to lend added legitimacy to the case study approach. Abduction, making a judgment concerning the best explanation for the data you are collecting, is useful terminology for describing an essential part of the process. Rather like Stake's 'naturalistic generalisations', 'phronesis' is judgment based on personal experience and practical knowledge. It is this common-sense, practical approach to knowledge-building that best suits my research task and in the execution of my case study I wish to abide by Robson's proposal that we should 'demystify the enquiry process – consonant with not compromising its rigour. We are building on and systemising common sense and ordinary knowledge, not replacing them' (Robson, 1993:462).

### **5.8 Action research (a dimension of my case study)**

Through my research I wanted to contribute to useful change, believing that, in the words of Kurt Lewin who coined the term 'action research', 'research that produces nothing but books will not suffice' (Lewin, 1946). Action research is about helping to develop practice (McNiff et al., 1996; Somekh, 2006; Thomas, 2011) and it gave an important dimension to my case study. Staff at the two settings worked with me to develop practice and knowledge for working inclusively with children with autism in this aspect of the case study. Most approaches to research have rules about not influencing the object of the research through intervention (McNiff et al., 1996) and this is one of the ways in which action research differs. Another defining feature of action research is that, as it seeks to bring about change, it has a basis in values (McNiff, 1996; Somekh, 2006). Somekh (2006) takes this idea further, saying that action research 'starts from a vision of social transformation and aspirations for



greater social justice for all' (p.7); these words resonated with me as I thought about my study, both in relation to the children with autism and in relation to the participants themselves. In addition to a notion of social justice, I also had in mind the notion of empowerment as the shared collaboration and shared thinking about the problems to be solved, was also about empowerment of the participants.

Based on a social-constructivist approach to learning (Vygotsky, 1978), my work with the teachers in the two schools comes out of an understanding that individual developmental change and learning is rooted in society and culture. In other words, the development of practice had to be culturally appropriate for the particular local needs of the participants. The action research element of my case study was participatory and involved practitioners thinking and making choices (Thomas, 2009) so that it had practical immediacy and prompted reflection and new learning. The nature of action research is iterative and cyclical (Denscombe, 2010; McNiff, 1996; Somekh, 2006; Thomas, 2009), and requires a cycle of action, planning and critical reflection leading to further action. There are numerous complex diagrams to illustrate this process. I like the simplicity of Thomas's model (2009) (Figure 11), although it may not accurately depict the multiple complexities of the action research process in this part of my study, as I will outline below.

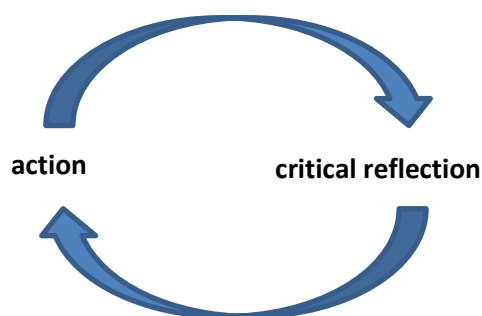


Figure 11: Action Research Cycle. (after Thomas, 2009)

To this process, McNiff (1996) brings the notion of action being more than a simple carrying out of a task, it is about 'praxis rather than practice' (p.8). In other words it is about taking informed, committed action and developing knowledge about practice. This development of understanding, so very important in the field of autism, as well as practical skills, is what the participants and I tried to achieve together and the dialogic process we went through was one of planning, doing, reflection and learning. Analysis of this forms an important part of my findings for this strand of my research (Chapter 7). I now give an overview of how the action research process worked in my study and how I involved the participants in the process of change.

The way it worked in my study was developed through negotiation and collaboration with the participants and this played out differently in each of the two cases. In both schools, at their request, the collaboration was launched with whole-school workshops about autism education and about the research. Programmes for this were negotiated beforehand with key staff. After this, self-selected groups of staff at each school opted to be members of the two focus groups to work with me and each other to develop practice and knowledge. In both centres the pupils with autism became the focal point for the action research cycle of discussion, action and reflection and this gave an immediacy and practical relevance to the research, shaping the way that it developed. A detailed explanatory diagram of this process at one of the schools comes later in Chapter 7 (Figure 39, p.223 ). For now a simple example of one cycle of the action research process is given in Figure 12.

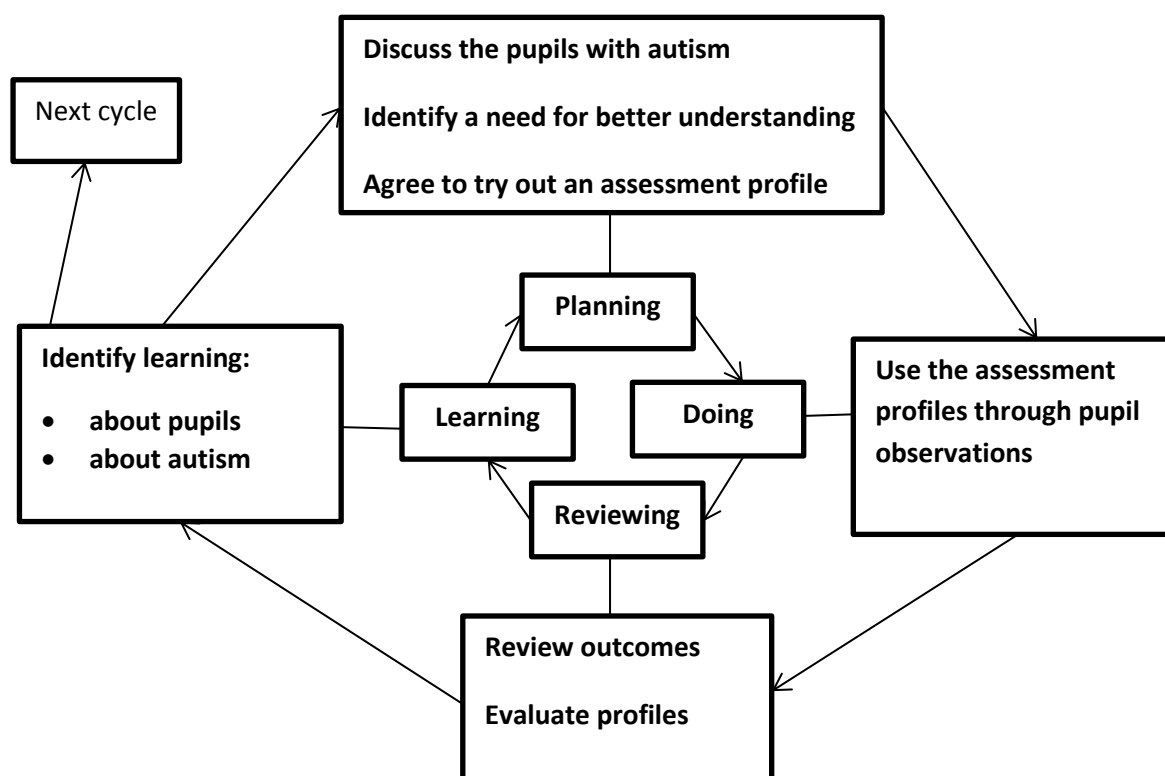


Figure 12. An example of one phase of the action research cycle at Friends School (adapted from Kolb 1984)

The stages of planning and reviewing with the participants were necessarily ad hoc as they took place during the working day and of course not all staff would be available at the same time. When I was in the UK we held discussions via Skype on eleven occasions although, as discussed below, the technology to do this sometimes let us down. Also, at Friends School, we held three participatory workshops over the research period, in addition to the introductory whole-staff workshop, enabling us to share and consolidate the learning that had taken place. We also built a Wiki as a resource bank for documentation that was used and developed during the research. This is described below in the methods section.

The action research dimension developed very differently in each of the two educational settings. Apart from their differences in terms of location, the social

background of their students, their historical beginnings, curriculum and affiliations, another significant factor was that whereas the Friends School was involved from the outset, the second setting, Amira Basma Centre only became involved eighteen months later, in November 2012, so their involvement was much less. The differences in the way I worked with the two settings reflects the emergent design of my research; it was also aligned to an IPA stance whereby I sought to engage with participants in a flexible way that fitted in with their lived experience (Smith et al., 2009). For example, whereas staff at FGS wished to enhance their capability to include their four autistic pupils into mainstream classes, at ABC the school wanted to prepare for the future inclusion of pre-schoolers in their autism unit. Further detailed examples of this approach are given in Chapter 7 where I discuss findings from the case study.

## **5.9 My role as researcher**

Throughout the study, an interpretative approach required sensitivity to context, an openness to what was there, a cautious and reflective approach, together with a duty of rigorous analysis. IPA encouraged my awareness of the dual role of both trying to make sense of the participants' world whilst aware of and not denying my own understandings, beliefs and opinions as well as the recognition that my research choices would undoubtedly be influenced by my own values and sense of what mattered. In the first strand, (the interviews and visits of the contextual enquiry) IPA helped me to define my role as empathic listener willing to follow the respondent's interests or concerns. In strand two of my research, however, working with teachers in the action research dimension of the case study, my role went well beyond the

parameters of an IPA study in that I had a purpose in addition to trying to understand the situation. The motivation for my research was a wish to offer something useful in relation to a perceived need; it had an emancipatory aspect and was about empowering participants with the aim of building capacity and effecting change in relation to the inclusive education of autistic children in Palestine. The researcher role was complex: I was an active participant, not an outsider seeking only to understand, but influencing the research process and working together with participants to bring about change. I still viewed participants as 'the experiential experts on the subject' (Smith & Osborne, 2008:59), but I was bringing my own experiential expertise, such as it was, to the work we did together.

My role as a researcher was set out clearly in explanations given both verbally and in the participant information documents, following ethical protocols, but I was never entirely able to shift their desire for me to show them what to do. This area remained unresolved.

#### **5.10 Ethics**

Before embarking on my study my research proposal was scrutinised by the Ethics Committee of the University of Birmingham. It was a lengthy and complex process culminating in ethical approval for my research (Ref. ERN\_11\_04\_23). In addition to the standard information required to satisfy themselves of the ethical propriety of my study the Committee also wished to know about the status and financial allegiances of QCERD, my research partner in Palestine. The translator supplied by QCERD was required to sign a confidentiality agreement (CD:B2) drawn up by the legal department at UoB, thankfully simplified to reduce the amount of legalese, to say that she would maintain the confidentiality and anonymity of participants. The committee

also wanted assurances of my safety in Palestine and to know about visa requirements for my visits there. The Committee was concerned to ensure the best interests of participants in Palestine. For this I showed how I would enable participants to give informed consent for their involvement by providing examples of the participant consent documents (Appendix 7 and CD:C3) and participant information documents (Appendix 8 and CD:C1) that I would use to provide information about the purpose of the research, confidentiality, the right of participants to withdraw without negative consequences to themselves, storage and retention of data as well as contact details for myself and my research supervisor. The Committee also wanted assurances that child-safeguarding legislation would be adhered to and that children's rights would be protected. Evidence for how I would ensure this was also provided within the Participant Information for Parents and within the Child Information and Assent Form<sup>15</sup> (CD:C5). Documentary and digitally recorded data was stored for the required time limit in a secure location at QCERD and remained confidential and anonymous. The committee also required a sample questionnaire (Appendix 1) and interview schedules (Appendix 2 and CD:2-5).

### **5.11 A mixed-methods approach**

A mixed methods approach was employed to gain broader answers to my research questions. Although I was clear about the purpose of my research and had formulated the questions that I needed to ask, the way in which my research would develop was not clear from the outset. I sought opportunities to broaden my understanding as I progressed and, through on-going reflection, allowed the design

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<sup>15</sup> In the event the Child Assent Form was not used and the involvement of children was only through classroom observations. For this, parental consent was obtained both verbally by the school staff and parents were provided with the Participant Information for Parents. The issue of child involvement is discussed further in Chapter 6

of my research to emerge. This flexibility of approach was particularly important for my research as there was so much that I did not know about the Palestinian context and the mixed methods approach helped to gain a broader understanding of my research topic. For example, whereas questionnaires provided useful qualitative and quantitative data, this was restricted to a set of questions chosen in advance. Semi-structured interviews, on the other hand, allowed me to probe areas of interest that arose and to target questions more individually. Yet again, focus group discussions, in the way I used them, gave me access to thoughts and feelings that arose more independently of my own direct involvement. To answer my research questions I needed this diversity of methods. As an example: from my semi-structured interviews and unstructured discussions with teachers I had formed the view that very little was known about good educational practice in relation to pupils on the autism spectrum and this view was strongly substantiated when I analysed and quantified the data from questionnaires and recorded workshop discussions with a large group of Inclusive Education Counsellors (IECs), the professionals who, it could be argued, might have been expected to have the greatest knowledge in this area.

My study is fundamentally qualitative although some data are quantitative, adding depth and substance to the qualitative findings. The distinctions between qualitative and quantitative approaches break down so that the dividing line between the two is not precise and they are not incompatible alternatives (Denscombe, 2010). For example, when I seek to quantify the number of IECs who hold a medical view of autism, I am dealing with the quality of their thinking and I would argue that this data is both quantitative and qualitative. Different research questions were approached by the most suitable methods. For example, 'how is autism understood in Palestine?' is

a question that was most usefully addressed in the questionnaire used in the Ministry workshop whereas the experience of families emerged most graphically from semi-structured interviews. I found that careful planning was needed in using a mixed-methods approach to consider how the data from one method related to that obtained in another way; there needed to be a purposeful, clear rationale for my selection of methods rather than ad hoc choices. Hence, for example, I found that analysis of data from initial questionnaires given to participants was useful to compare with data from semi-structured interviews. In my analysis, as well as looking for corroborating data I have also sought instances where the different data were contradictory. An overview of the methods used is given in Table 5. I say more about each method in the next section and give references to the appendices where the reader may see the various research instruments that I mention.

Method	Details	Participants
Interviews	Semi-structured using a schedule  Recorded and transcribed	Key staff at the two schools (7)  Parents (6)  Ministry of Education officials (2)  Community providers (3)  University Academic (1)
Discussions	Unstructured / informal  Notes taken	Teachers (4)  Community providers (4)  Parents (1)  University academics (2)
Questionnaires	Initial participant questionnaires (schools)  Focus group questionnaires  Evaluation of the action	All staff at the two schools: 27 (FGS) + 24 (ABC)= 51 total  Focus group members at both schools 14 (FGS) + 11 (ABC) = 25 total  Focus group members at FGS (9)



	research	
	Initial participant questionnaire	Inclusive Education Counsellors and Education Supervisors (36)
Focus group discussions	Semi-formal with flexible agendas Face-to-face and on Skype	Focus group members (both schools) (Variable numbers)
	As part of a 2 day workshop	Inclusive Education Counsellors and Education Supervisors (40)
Observations	Classes including pupils with autism (using an observation schedule)	Friends School
	Autism unit	Amira Basma Centre
	Centres of community provision	Annahda Women's Centre Star Mountain Centre, Surda Friends of Autistic Children Centre Tulkarem Rehabilitation Centre Terres des Hommes, Jerusalem Resource Centre, Faisal Hussein School, Ramallah
Field notes	Note books	
Wiki	Devised to provide and share information	Both focus groups
Final Study Day	A presentation of my research and group discussions.	Participants from both strands of my research plus others. <ul style="list-style-type: none"> <li>• Teachers and educators (18)</li> <li>• Parents (6)</li> <li>• Community providers (17)</li> <li>• Health professionals (13)</li> <li>• Ministry of Education staff (6)</li> <li>• University staff (6)</li> <li>• Journalists (2)</li> <li>• Total (68)</li> </ul>

Table 5: Methods of data collection

### 5.11.1 Interviews

I developed semi-structured interview schedules (Appendix 2 and CD:2-5) for my contextual enquiry. The semi-structured interview model was chosen as more open and exploratory than the structured model, allowing the interviewee greater influence

over the direction of the interview and affording the potential for her to address issues of importance which I may not have considered beforehand. The design, conduct and analysis of the interviews drew on IPA, as discussed above, although some of my questions were perhaps more about practice than would normally be the case in IPA. The schedule included broad topic areas with open questions and follow-up prompts to use where appropriate so that the interviews were guided by the schedule rather than dictated by it (Smith and Osborne, 2008). There were five versions of the interview schedule as I wished to tailor my questions to the background or role of the interviewees. For example, as shown in my research questions (Figure 10) I wanted to find out about the experience of families and a parent would perhaps have a different set of perceptions from a Ministry official. At the beginning of each interview, I explained the purpose of the research, thanked the interviewee for agreeing to meet me, negotiated time limits and explained what would happen to the data from the interview. I requested that I should be allowed to record the interview using a digital voice recorder. Following IPA guidelines (Smith & Osborne, 2008) I aimed, through body language, tone of voice and facial expression, to achieve a relaxed and friendly rapport during the interviews; I ordered the questions so that the simpler ones came first and more sensitive questions involving feelings and attitudes came later. My lack of facility with Arabic may have made the occasion seem more formal for the interviewee and highlighted my 'outsider' status (Robinson-Pant, 2005). Where the interviewee's language skills and preference made it possible, interviews were conducted in English, giving a greater degree of shared understanding and reciprocity than when, as on some occasions, it was necessary to work with a translator. For a number of the interviews that were conducted in English the

interviewee and I found the presence of a translator was helpful to clarify complex points or uncertain terminology. In working with a translator it was important to be explicit about their role and have a shared understanding about how to work together. For example, the translator should not censor or edit what is said, but give as faithful a rendering as possible of what has been said. A useful checklist for working with an interpreter (Laws et al., 2003) provided guidance as I worked to ensure the validity of my interview data.

### 5.11.2 Questionnaires

I used four different questionnaires, as indicated above (Table 5), each designed for a purpose (McNiff et al., 1996). Table 6 sets out the differing purposes of the 4 questionnaires, where they were used (research phase) and the research questions to which they related.

Questionnaire	Research phase	Purpose	Example
Initial participant questionnaire - schools	Case study	Explore answers to research questions 1-4 <ul style="list-style-type: none"> <li>How is autism understood?</li> <li>How are children with autism identified educated and supported?</li> <li>How is inclusive education regarded?</li> <li>What are the aspirations of these participants?</li> </ul>	Appendix 1
Focus group questionnaire (ABC)	Case study	Identify wishes of focus group participants  Explore answers to research question 4 <ul style="list-style-type: none"> <li>What are the aspirations of these participants?</li> </ul>	CD:C7
Evaluation of participant experience (FGS focus group)	Case study	Evaluate participant experience in the research  Explore answers to research questions 4, 6 <ul style="list-style-type: none"> <li>What are the aspirations of these participants?</li> <li>To what extent are ideas from the UK and elsewhere useful?</li> </ul>	CD:C8

MoEHE workshop Initial questionnaire	Contextual enquiry	Explore answers to research questions 1-4 <ul style="list-style-type: none"> <li>• How is autism understood?</li> <li>• How are children with autism identified, educated and supported?</li> <li>• How is inclusive education regarded?</li> <li>• What are the barriers, opportunities, aspirations?</li> </ul>	Appendix 9
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Table 6: Purpose of the questionnaires

The advantages of questionnaires included an efficient use of my time, the option of anonymity for respondents, and standardisation of questions (Munn & Drever, 1990). I took the precaution of piloting the initial participant questionnaires with a different group of Palestinian teachers and this was helpful in identifying one point of confusion and the need for one additional question. A great deal of care was needed for the wording of the questions to avoid ambiguity and questioner bias, as Munn & Drever (1990) caution. The complexity and importance of this issue of ambiguity and bias was greatly increased by the need for the questionnaires to be translated into another language and the answers to be translated back again. There are significant challenges in producing translated questionnaires (Behling & Laws, 2000; Harkness et al., 2004). I was aware that it can be difficult to achieve semantic and conceptual equivalence across languages and across cultures (Behling & Laws 2000; Hunt & Bhopal 2004) and, faced with this difficulty, my translator might deal with slight ambiguities or uncertainties by giving an ambiguous or inadequate translation (Harkness et al., 2004). There was also the possibility that this difficulty might be duplicated again when the respondents' answers were translated back from Arabic into English. I sought to minimise these challenges by calling on the support of a bilingual consultant who also had knowledge and a good understanding of the terminology used in the field of autism and education. Simplicity and clarity of language are important for questionnaires in any language, but in this case, where

translation was needed this was of the utmost importance and the wording was chosen with translation in mind. The issue of translation is one that I return to in the final chapter of my thesis.

### **5.11.3 Focus groups**

Further data from the MoEHE workshop was obtained through a series of three group discussion tasks (CD:E3) from which the verbal feedback was digitally recorded. On this occasion my use of focus groups as a method for data-collection was different from the way it is described in the literature (Denscombe, 2010; Bell, 2010; Thomas, 2009), in that I did not facilitate the discussions in person, only through the written guidance of a set of questions, leaving the group to determine the direction of the discussion. This left them free to discuss the issues in Arabic without the hinderance of translation; it also enabled them to be in smaller groups of five or six rather than a group of forty. These focus groups consisted of MoEHE professionals who had a shared interest and knew each other and the data gave access to their thoughts and feelings and enabled me to explore answers to research questions 2,3 and 4:

- How are children with autism identified educated and supported?
- How is inclusive education regarded in Palestine?
- What are the barriers, opportunities and aspirations?

I also used the term 'focus group' in a different sense to describe the two groups of teachers and practitioners from the two schools who had opted to participate in the action research. They are 'focus groups' in that they are groups with focused attention on a given topic; but they also came together with me, as well as without

me, to discuss and evaluate the research, providing valuable naturalistically acquired data.

#### **5.11.4 Observations**

Observation, carried out in a questioning and open manner, was used to investigate and interpret situations that I encountered in my research. Clough & Nutbrown (2002) talk of this way of observing, which they call 'radical looking' as being one which is about looking for meanings as well as evidence. Observation as a method has taken many forms in my research. I agree with Thomas (2009) that it is 'one of the most important ways of collecting data' (p.183), but I recognise that this approach was limited by my lack of access to the spoken and cultural aspects of my observations. I needed to be cautious in my interpretations, as for example when I observed the body language of participants in one of the focus group discussions and thought they were quarrelling ferociously but my translator assured me that they were having an amicable exchange of ideas. Informal observation was an important aspect of my contextual enquiry. I believe that I was able to understand a lot about the ethos and practices of the schools, centres and institutions I visited through seeing the material conditions and through my 'reading' of non-verbal communication. Data from these observations is in my field notes.

In the participating schools I conducted semi-structured observations in classes where there were pupils on the autism spectrum, using an observation nudge sheet (CD:C9) to guide my observation. In addition I gave my translator an observation schedule (CD:C10) which I developed, based on the SCERTS model (Prizant & Whetherby, 2006), to guide her observation of the communicative interactions involving the pupils with autism. Immediately after the observations we discussed

and compared our perceptions of the observation. Observation is an important aspect of good autism practice (Prizant & Whetherby, 2006) and, as well as modelling this for the teachers in the way I have just described and feeding back my findings to them in follow-up discussions, I also devised a more comprehensive observation and assessment profile (Appendix 6) for each of them to use as part of the action research, again based on the SCERTS model. Tilstone (1998) and Hart (2000) write of the importance of encouraging teachers to observe and lament that this is rarely a significant part of teacher training. Tilstone warns that, without proper preparation, we are in danger of seeing what we are looking for and may only look for things we know about. The profile I gave them proved to be a revelatory way of enabling the teachers to observe, collect data and improve their knowledge of the pupils. Teachers' evaluations of the profile provided data about the usefulness of this approach, making it doubly useful for the research.

#### **5.11.5 Field Trips and Notes**

Field notes were made where possible soon after field work and sometimes during field work, in observations, meetings or workshops for instance, although there was always a need to be sensitive to how note-taking would appear to participants. The field notes usefully linked themes running through the different strands of my research and I refer to and quote from field notes several times in my findings chapters. Field notes were an important aspect of my interpretative enquiry and gave a useful record of on-going reflections and the development of my thinking, especially in relation to the double hermeneutic as I grappled with trying to understand the experiences of the participants whilst aware of my outsider status. Field notes (Table 7) served both to stimulate and to hold a record of some of this process.

Field Trips to Palestine		
1	October 2011	2 weeks
2	March /April 2012	2 weeks
3	October / November 2012	2 weeks
4	April 2013	2 weeks
5	November 2013	2 weeks
6	February 2104	1 week

Table 7: Field trips to Palestine

### 5.11.6 The Wiki

As part of the action research I developed a Wiki (Figure 13), an on-line community space for participants to share, communicate and support each other during the research project. This provided them with access to a wealth of materials, some of which I had translated into Arabic. It was also a place to store resources developed as part of the research.

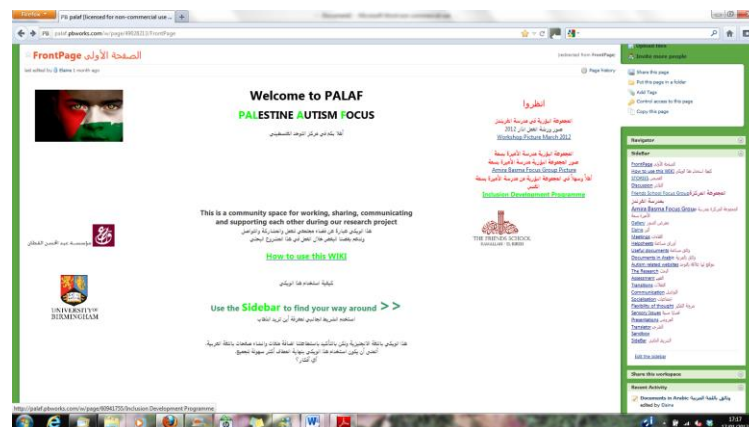


Figure 13: Front page of the Wiki

Tinsley and Lebak (2009) expand on the idea of the zone of proximal development (Vygotsky, 1978) to see how collaboration between teachers enables development of



individual practices. With severe travel restrictions in Palestine, as described in Chapter 2, on-line communication offers an attractive means of enabling a group of professionals to share ideas. An evaluation of the Wiki provides data to draw on in thinking about the usefulness of such a resource and how it might be developed and maintained. The potential of online collaboration for creating CoPs is one that I return to in Chapter 7.

### **5.12 Study Day**

My fieldwork culminated in a Research Report (Ashbee, 2013) of 37,000 words that was translated into Arabic and distributed to participants and other interested parties, together with an executive summary (CD:J1). This report formed the basis for a Study day hosted by QCERD at which, after my presentation of research findings and recommendations, participants were divided into five discussion groups randomly allocated in advance. With briefed group leaders, they were asked to divide their time equally between three questions given on a handout (CD:J4). An hour was allocated for the discussions, followed by feedback from each of the groups with main points summarised on flipcharts which were later collected, transcribed and translated for analysis. Each group's verbal feedback, in Arabic, was translated for me *in situ* and I made field notes of key points. These field notes supplemented the flipchart notes in the analysis of the group discussions. Chapter 8 discusses findings from the Study Day.

### **5.13 Challenges and Limitations**

Travel restrictions had a far-reaching impact. As a visitor from the UK, I was able to travel by taxi albeit with long waits at Israeli checkpoints or lengthy diversions to

avoid them. My translator however was required to have an Israeli permit to travel and sometimes the permit was not granted or only granted at the last minute so that our schedule was uncertain. Even with a permit, she could not accompany me in the taxi to Jerusalem, for example, as she was obliged to pass through the Qalandia checkpoint on foot to have her permit checked, risking delay or inexplicable denial of passage. Restrictions hampered the research plan to bring together the participants from the two schools which we only achieved once with great difficulty and without all of the participants. One limitation of my study is that it was not feasible for me to include Gaza in my research because of extreme travel difficulties and security risks, although over a third of the population of Palestine is in Gaza (PASSIA, 2011). Therefore my study was confined to the West Bank and East Jerusalem.

Researching in a different culture and language was also a challenge, even with the welcome support of a translator. As well as practical and ethical concerns (Laws et al., 2003), it presented a barrier to the interpretation of nuanced meanings (Bellos, 2012), especially significant in the field of autism and disability where language is dynamic and changing. Working across two languages and needing to find parity between them I became increasingly aware of the important implications of this issue. An early unsettling revelation that my use of 'autism' had been translated as 'autistic disease' in Arabic and 'clumsy movements' as 'idiotic movements' for a presentation I was giving, highlighted a need for safeguards in the translation of research instruments, data and presentation materials and I did my best to ensure this in several ways. I enlisted the support of a trusted friend and ally, one of the participants, who had excellent English and an understanding of terminology relating to autism and inclusion, although this was not always possible as she had her own

busy life and important work. My translator was a tower of strength and I have nothing but praise for the support she gave me. I provided her with a glossary of terminology in English and Arabic and we spent many hours discussing autism and language. I wrote materials straightforwardly with translation in mind. It was not possible for me to have a top-notch bilingual team to prepare and translate questionnaires, as recommended in the literature (Behling and Laws, 2000).

Another challenge, as discussed by Boromisza-Habashi (2012), related to time implications and access challenges concomitant with conducting research in a distant country. My time in Palestine amounted to only two weeks twice a year for the duration of the research (Table 7, p.107). My plan was to supplement this with emails and skype from the UK and although this was valuable it was not entirely successful as internet links were often impossibly poor or lost altogether.

Changes taking place in the two case study settings presented further challenges, as both of them underwent leadership changes with profound implications. Friends School for instance, experienced a tumultuous time of change with two new directors within so many years, each with their own far-reaching agendas. This pressure to change the way they worked made it more difficult for participants to commit themselves to the research as much as they and I might have wished.

There were also challenges relating to my role. Hearing that an autism 'expert' (not my choice of epithet) was in Palestine drew parents wanting advice from me or a diagnosis for their child. Sometimes the simple need for human support and listening seemed more important than the need to protect my precious field work time, as for example when a participant wanted to talk about the eviction order issued to her

family in Silwan, an area of Jerusalem that is being cleared by the Israelis. Or when another participant wanted to tell me about her son, in an Israeli prison for throwing stones at soldiers. Any researcher faces such intrusions into their schedules, but I mention these examples to illustrate how the context of my research impacted on me. This was especially significant as my time in Palestine was so limited.

#### 5.14 The organisation of the data

Despite challenges a large body of data was collected. For the purpose of analysis the data were grouped into four sets (Figure 14). Data sets 1 and 2 are primary data drawn from strand 1 of the research (the contextual enquiry); Data set 3 is primary data that belongs to strand 2 of the research (the case study); Data set 4 (the final study day) is supplementary data gathered after completion of the primary data collection.

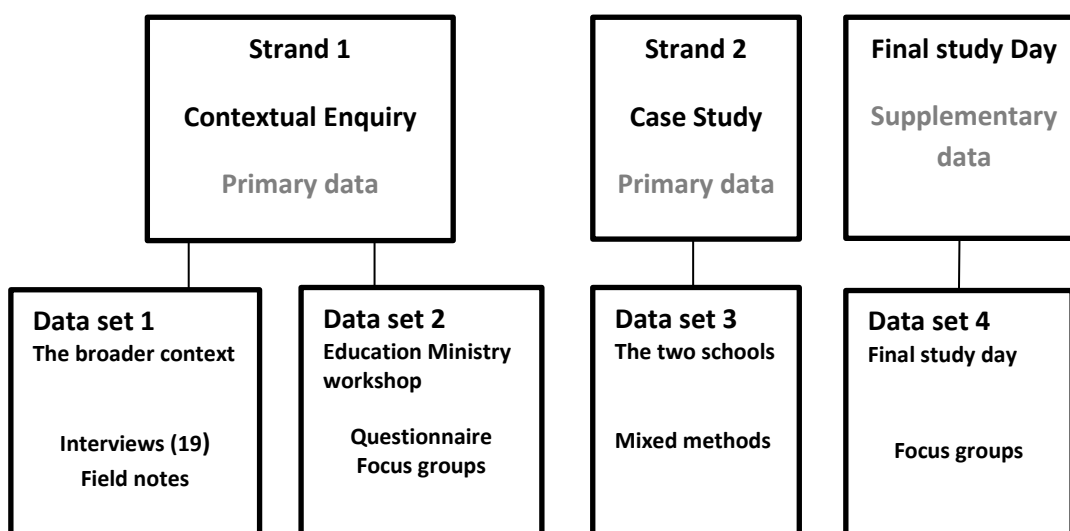


Figure 14: The four data sets

Research findings are presented in the following three chapters. An overview, showing the interrelationship of the four data sets, is given in Figure 15.

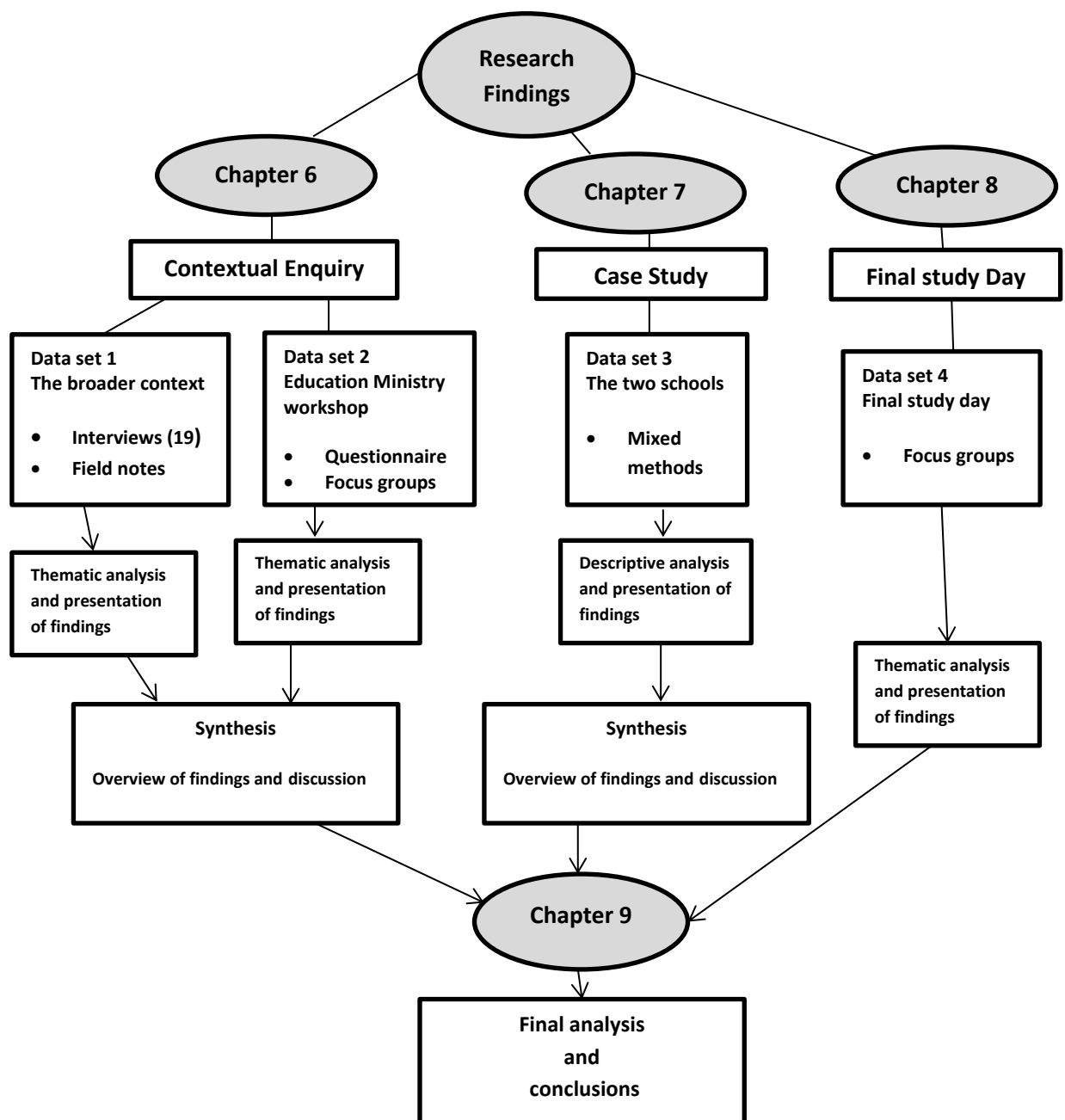


Figure 15: Structure of the data analysis in Chapters 6,7 and 8 and final analysis and conclusions in Chapter 9

## CHAPTER 6: FINDINGS FROM THE CONTEXTUAL ENQUIRY

### (Data sets one and two)

‘Autism is a ‘new area’ in Palestine and not widely understood by professionals or within society’

Ministry Official (M1)

This strand of my research<sup>16</sup> sought a wider understanding of the issues that would impact upon the education of children with autism in Palestine. Whereas my case study looked at the microcosm, the contextual enquiry looked at the macrocosm. The data for this fall within two main data sets (Figure 16). Data set one consists of 19 semi-structured interviews as well as observations recorded in my field notes and data set two is drawn from a questionnaire and focus group discussions at the Ministry of Education workshop; these two sets of data are analysed separately before being discussed together.

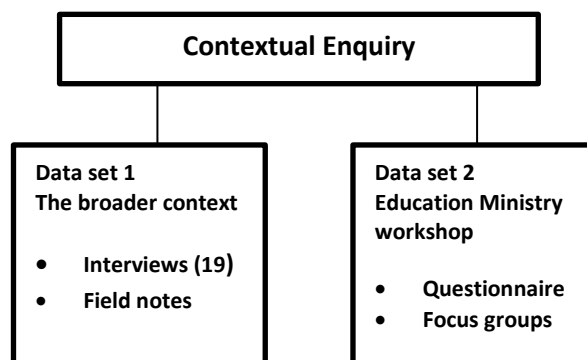


Figure 16: Contextual Enquiry – Data sets 1 and 2

### 6.1 The broad context: interviews and field notes (Data Set one)

Visits to centres and institutions in the West Bank and East Jerusalem provided answers to my research questions about the experience of children with autism and

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<sup>16</sup> The Contextual Enquiry ran contemporaneously with the Case Study strand

their families, practices and provision, knowledge, attitudes, as well as opportunities and challenges. The interviews took place in the West Bank and East Jerusalem with a variety of people at differing institutions (Table 8). The interviews form the bulk of the data within this data set. Interviews were audio recorded, with the consent of the participants, and later transcribed (Appendices 7 and 8 [examples] and CD: D1-6). As outlined in my research design chapter, my sample was purposive as interviewees were chosen who would give me access to a broad range of perspectives on my research topic. In a study about inclusion it was necessary to be as inclusive as possible and the importance of multiple perspectives is well documented in the literature on autism practice (Charman et al., 2011; NIASA, 2003; Parsons et al., 2009). Interviewees fell into six groups:

1. Parents
2. Teachers
3. Practitioners
4. Community providers (People in the community offering provision for children with special needs)
5. Ministry of Education staff
6. University researchers

Interviews explore participants' perceptions and experiences in relation to autism practice in Palestine. I used semi structured interview schedules (Appendix 2) to give flexibility and the opportunity for interviewees to expand on their own areas of interest and allow me to follow up initial questions with further probes. As explained in Chapter 5, interview schedules were adapted according to the status of the interviewee. About one hour in length, some interviews were conducted in English, and where this was not possible they were conducted with the help of a translator, as discussed in Chapter 5. Table 8 summarises information about the interviewees.

<b>Interviewee</b>	<b>Institution</b>	<b>Location</b>	<b>With translator</b>	<b>ID Code</b>
Parent 1	Friends Girls School	Ramallah, WB		<b>P1</b>
Parent 2	Friends Girls School	Ramallah, WB		<b>P2</b>
Parent 3	Friends Girls School	Ramallah, WB		<b>P3</b>
Parent 4	Amira Basma Centre	East Jerusalem	Yes	<b>P4</b>
Parent 5	Amira Basma Centre	East Jerusalem	Yes	<b>P5</b>
Parent 6	Amira Basma Centre	East Jerusalem	Yes	<b>P6</b>
Teacher 1	Friends Girls School	Ramallah, WB		<b>T1</b>
Teacher 2	Amira Basma Centre	East Jerusalem		<b>T2</b>
Teacher 3	Friends Girls School	Ramallah, WB		<b>T3</b>
Teacher 4	Amira Basma Centre	East Jerusalem	Yes	<b>T4</b>
Teacher 5	Amira Basma Centre	East Jerusalem		<b>T5</b>
Practitioner 1	Amira Basma Centre	East Jerusalem		<b>PR1</b>
Practitioner 2	Amira Basma Centre	East Jerusalem		<b>PR2</b>
Community Provider 1	Annahda Women's Centre	Al Bireh, WB	Yes	<b>CP1</b>
Community Provider 2	JACCO <sup>17</sup>	East Jerusalem	Yes	<b>CP2</b>
Community Provider 3	Friends of Autism Society	Surda, WB	Yes	<b>CP3</b>
Ministry of Education Staff 1	Ministry of Eduaction	Ramallah, WB	Yes	<b>M1</b>
Ministry of Education Staff 2	Ministry of Eduaction	Ramallah, WB	Yes	<b>M2</b>
University researcher	Ahliya University	Bethlehem, WB		<b>U1</b>

Table 8: The interviewees

Analysis of the transcribed interviews drew on IPA in a process of iterative scrutiny that enabled me to anchor my interpretations in the accounts given by the interviewees. I was interested in the respondents' world and sought to draw themes

<sup>17</sup> JACCO: Jerusalem Autistic Child Care Organisation



from the data rather than imposing predetermined themes, although, unavoidably, my choice of questions would have strongly determined the broad themes. The procedure by which interviews were analysed now follows, illustrated by four extracts from appendices. A full analysis of the interview data is given after this account.

Procedures used in analysis of the interview data:

- 1 I transcribed verbatim each of the 19 recordings into Word documents, placing timings in a left hand column to aid retrieval of data. One recording was only partially audible due to background noise and the respondent kindly agreed to fill in the gaps in my transcription.
- 2 Interviews fell into six groups (parents, teachers, practitioners, ministry staff, community providers, academics). I selected one from each of these groups, chosen for richness of detail.
- 3 I read and re-read each of these six scripts to become familiar with the contents, using Word comment boxes to annotate interesting points and identify emergent themes. An example of this stage of the process is given in Figure 17. In the script used in this particular example there were 54 comments in total.

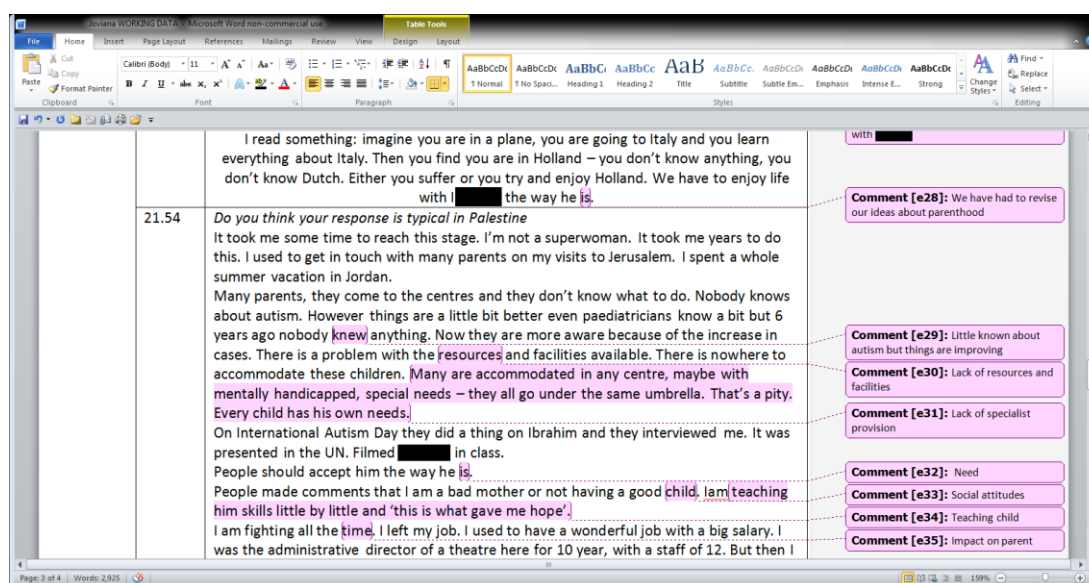


Figure 17: Screenshot from an interview script to illustrate 1<sup>st</sup> stage of analysis

- 4 From each of these six scripts I collated my comments into a further six documents. These were the emergent themes. Figure 18 gives an example taken from a different interview.

Interview with U1 – collated comments	
<ol style="list-style-type: none"> <li>1. Collaboration with Nablus p1</li> <li>2. Opposed to medical approach p1</li> <li>3. Medical approach is a big obstacle p1</li> <li>4. Diagnosis in 15 minutes p1</li> <li>5. Diagnosis – what we need p1</li> <li>6. Differences in autism p1</li> <li>7. Mental retardation hospital p1</li> <li>8. Autism and medication p1</li> <li>9. Parental pressure for medication p1</li> <li>10. Need to educate parents p1</li> <li>11. Need for govt action p1</li> <li>12. SEN - Progress in govt schools p1</li> <li>13. Praise for special ed sector in the MoEHE p2</li> <li>14. Lack of resources p2</li> <li>15. Council for SE ineffective p2</li> <li>16. No clear responsibility at govt level. P2</li> <li>17. Everyone's responsibility</li> <li>18. Diagnosis p2</li> <li>19. No autism category in office of statistics p2</li> <li>20. BAT for screening p2</li> <li>21. Palestine contributing to the international community p2</li> <li>22. Global centre for autism in Jerusalem p2</li> <li>23. Cooperation with Israelis is OK for medical issues p3</li> <li>24. Possible development of an institute for autism in WB p3</li> <li>25. Business interests in autism provision</li> <li>26. Institute should be linked to research, not business p3</li> <li>27. Importance of parents p3</li> <li>28. BAT p3</li> <li>29. Importance of working with parents p3</li> <li>30. Current practice in autism p3</li> <li>31. Speech therapy and autism – bad practice p3</li> <li>32. Development of BAT p3</li> <li>33. Cultural differences and BAT p3</li> </ol>	<ol style="list-style-type: none"> <li>34. Cultural differences and BAT p3</li> <li>35. People write and speak in an indirect way / not straight p4</li> <li>36. Getting parents views p4</li> <li>37. Shopping for a diagnosis</li> <li>38. Poor practice in diagnosis / babysitting p4</li> <li>39. Institutions for autism and sen p4</li> <li>40. Religion and charity are not the answer p4</li> <li>41. Hurting the children – religious bodies p4</li> <li>42. Anecdote of child receiving inadequate diagnosis. P4</li> <li>43. Diagnosis p4</li> <li>44. S's approach to diagnosis p4</li> <li>45. Need to be honest about the situation we have, before we can improve it. P4</li> <li>46. 1,500 shekels for a diagnosis p5</li> <li>47. Diagnosis should be linked to therapy p5</li> <li>48. Diagnosis should not be a business p5</li> <li>49. Schools refer to these institutions p5</li> <li>50. Against private education p6</li> <li>51. Need for guidelines for autism p5</li> <li>52. Need for national standards p5</li> <li>53. Advice to remove uterus p5</li> <li>54. Need for greater social awareness and within the medical profession p5</li> <li>55. Dream of a national centre p5</li> <li>56. Need to protect children with autism p5</li> <li>57. Rights p5</li> <li>58. New sen prog at Al Quds uni p5</li> <li>59. SEN is a moral issue not a business issue p5</li> <li>60. Responsibility of university to build policy p5</li> <li>61. Welcome for my research p5</li> <li>62. Wanting to learn from others p5</li> <li>63. S's diploma course p5</li> <li>64. Praise for / collaboration with G [REDACTED] p5</li> <li>65. Need for real heart and commitment p6</li> </ol>

Figure 18: Emergent themes from one script

- 5 An iterative process of reading and rereading the six scripts enabled me to cluster emergent themes and identify eight dominant or, to use the terminology of IPA, 'superordinate' themes (Table 19). I sought to follow IPA guidelines (Smith et al., 2009) and draw themes from the data although, as discussed, my choice of questions partly foreshadowed themes that would emerge. Rather than seeing this as a failure of validity, awareness of the double hermeneutic encouraged me to have a self-aware confidence in my own interpretations while delving into the issues that were significant for the participants.

Superordinate themes	
A.	The experience of parents and families
B.	SEN and disability in Palestine
C.	Diagnosis of autism
D.	Autism practice and provision in Palestine
E.	Social attitudes and perceptions
F.	Inclusion
G.	Barriers to progress
H.	Opportunities and aspirations

Figure 19: The eight superordinate themes

- 6 Codes (A to H) were allocated to each of these eight themes (Figure 19)
- 7 I made a proforma to collate data within these eight themes from the remaining scripts. Looking only for data that fell into these eight themes risked overlooking other significant issues raised by interviewees, so I included a space on the proforma to record other issues.
- 8 The remaining 13 scripts were scrutinised and sections copied and pasted to illustrate and amplify each of the themes. The themes were sufficiently broad to accommodate almost all of the data with minimal exceptions.
- 9 For each of the superordinate themes I made a combined table of the data (eg. Figure 20).

Theme G: Barriers to progress	
Respondent	Data
M2	Intifada meant that accessibility and moving around school was very difficult.
	It was planned that the load would be decreased (for the focus teachers) but it was not accepted

	for financial reasons, by the Ministry.
	In 2006/7 the Ministry said no extra teachers, not reduced load. Can't afford it. So they trained one teacher from every school – 36 hours training.
	And this teacher was responsible for coordinating between the school and the IECs, but they don't have any extra time to do this. They help us with statistics and collecting information about the identified needs.
	There are no courses in special education in the university.
	We know there is a demand but we are not able to meet it at the moment.
	No clear policies. We want instructions on how to assess the children.
	The challenges were seen but the successes were not easily seen.
	Working alone, without a team, has been very difficult. Too much to supervise: resources rooms, inclusive education, centres, training – overload becomes a barrier. Another barrier: lack of specialisation. Financial restrictions.
M1	Initial teacher training does not include SEN, and certainly not autism.
	There are no universities in Palestine that offer courses in autism or any special needs courses.
	30 IECs covering more than 1200 schools in Palestine in 16 Directorates .with only 2 special education supervisors They work to support schools to be able to include children with SEN (through solving the barriers to inclusion ), but their work load is huge and they each attempt to address the needs of all areas of SEN.
	They lack a thorough professional training in SEN (IECs).
	Teachers often feel that they are unable to meet the needs of children with SEN because, as well as a lack of training, they have 27 classes each week and they feel that they do not have time to teach children with SEN or autism.
PR1	We live in a country where we have a problem every single minute – not just autism, not just poor. The occupation is a big challenge for us. If there is no checkpoints between Jerusalem and the WB it would be easy for the people to come here, easy for us to transfer children.
	All the centres they don't have money.
	But it cost money and it is not easy.
	It is not easy because of their West Bank ID. Otherwise they have to pretend they have a note from a doctor to come here.
	They can't come to us because of the checkpoints.
PR2	...
T	The checkpoints make problems because now we spend hours on the checkpoints.
T	There are many causes behind the children being violent. First is what they live and what they see. It has to do with the political situation, I mean just going through a checkpoint makes them see the violence. It doesn't have to be violence by hitting or by. It's violent speech, verbal aggression. Also

	<p>the political situation, when there was the split between Gaza and the West Bank we immediately started having students at the school making these different groups and fighting each other. Yes, because this is what they live: they hear the news on TV; they hear their parents talking about it. The war on Gaza: when there was bombing and shelling over Gaza some of the students said 'they deserve it'. This is what they hear.</p>
--	--

Figure 20: Extract from combined table

- 10 The analysis continued into the writing up of my findings from the interviews, using the combined tables as a basis for giving a detailed account of participants' responses.

Access to thoughts and perceptions of participants is likely to have been diminished by the need for translation between languages. Working with translators gave me less purchase on the nuances of meaning than would be available to a fluent Arabic speaker. Even when interviewees conversed in English, for my benefit, it was not in their mother tongue and, for this reason, was perhaps an approximation of what they might have said in Arabic. It seems likely that the language and cultural differences between me and the interviewees had an impact on the double hermeneutic, rendering the 'empathic hermeneutic' less prominent. The issue of subjectivity again came to the fore when I analysed the data from the interviews and found the dominant superordinate theme to be 'barriers to progress', in that it underpinned all the other themes. However, because my wish was for my research to be forward looking and to build on the positives, rather than focussing on the many very real limitations and obstacles to progress that are faced by Palestinians, I stopped short of making 'barriers' my opening or super-dominant theme. The analysis provided eight dominant themes (Figure 21).

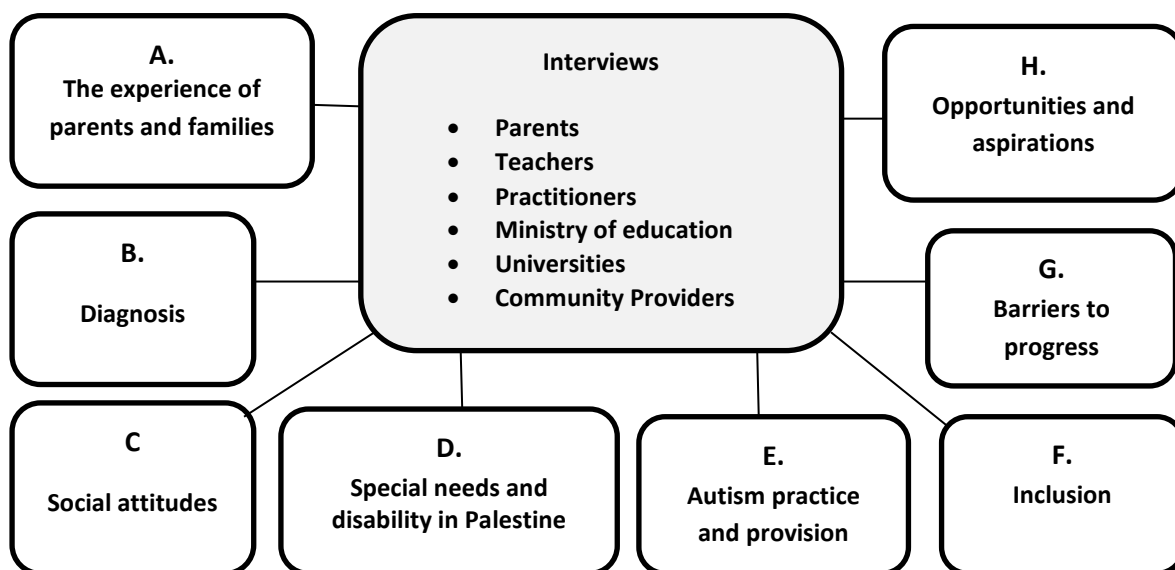


Figure 21: Dominant themes drawn from the interviews

### Analysis and discussion of the 8 dominant Themes

There is fluidity between the eight dominant themes so that they overlap and are not entirely distinct categories but rather a means of organising the data. In the following discussion, where I have needed to clarify the meaning of words from the interview transcripts, my own inserted words appear in square brackets. Names have been changed to preserve anonymity. Codes (shown in Table 8) identify the source of quotes taken from the transcripts. For example P2 = Parent 2. I also refer to my field notes (Table 9) which record additional conversations and observations. References to field notes are dated with the prefix 'FN' (eg. FN 5.4.13).

Field Notes used in Contextual Enquiry	
Data source	Date
Tulkarem Rehabilitation Centre	13.4.13
Researcher, An-Najah University, Nablus	25.4.13

Friends of Autistic Children Society	25.3.12
Friends of Autistic Children Society	18.4.13
Various	9.11.12
Amira Basma Centre workshop	1.11.12
Early Years Diploma workshop	3.11.12
U1, Ahliya University, Bethlehem	4.11.12
Star Mountain Rehabilitation Centre, Surda	6.11.12
Parent, Ramallah	7.11.12
Faisal Hussein School Resource Room	7.11.12
Terre des Hommes Inclusion project, Jerusalem	8.11.12
Parent and Head of Counselling and SEN, Jerusalem	8.11.12
Early Years Diploma workshop	16.10.11
Autism Conference, Bethlehem.	2.4.12
Amira Basma Centre autism unit	1.4.12
Parent, Friends of autism, Surda	25.3.12

Table 9: Field notes in Data set 1

The order in which I present the themes differs from the convention of moving from the general to the particular because I wish to start by taking the reader to the heart of the issue and give pre-eminence to the particular, the families with children with autism.

#### **Theme A: The experience of parents and families.**

I begin my discussion of the findings from the contextual enquiry with an extract from my field notes that encapsulates many of the themes that emerged.

Extract from field notes (3/12)
<p>A spring morning and I have come to the centre of the Friends of Autistic Children Society (FACS) in a village near Ramallah to meet the director and look round. The centre, set up by parents, is in a traditional flat-roofed limestone building and the front garden fills the senses with a profusion of white almond blossom. However, the generosity of the almond trees is not matched by an abundance of resources inside the building, and the solid permanence of the stone building is negated by the uncertainty and unsustainability of donor funding that dried up when the donors found another worthy cause elsewhere. Nevertheless I am warmly welcomed and shown around the rooms, freshly painted in pastel colours. The interview that I had planned to carry out with the director never really happens as, first, a new child visits with his bewildered parents and then an education supervisor calls in. But all was not lost: serendipity stepped in. The parents had recently been given a diagnosis of autism for their little boy, Ahmad, but no support or guidance, and were worried about his future. They had two older children and had realised early on that Ahmad was different. The first doctor they saw ruled out the possibility of autism because, they were told, Ahmad liked to watch TV. A year later autism was confirmed by a different doctor. The parents had decided not to tell family and friends of the diagnosis, preferring to say that Ahmad had 'speech problems' because they felt that Palestinian society did not understand autism and thought it meant that the child was mentally retarded. While the parents asked questions about the provision at the centre I was able to listen in, with their consent, as my translator whispered a translation of the conversation in my ear. It was also recorded. The parents learned that the centre takes children aged 3 to 14 or sometimes older, and that they had 12 on the books at that time. Parents had to pay a modest fee and most children came two or three times a week as that was all they could afford. They were told that the centre does not take 'violent' children but only those who are 'good'. Children are assessed and given an individual education plan and working together with parents was seen as important. Staff had not had training in autism but had developed some skills in working with the children and used PECS to support communication.</p> <p>The arrival of the education supervisor added a new dimension to the discussion. She took a great interest in Ahmad and after watching him for several minutes told the parents that he did not have autism. The reason for her assessment was that Ahmad made eye contact and it was her belief that children with autism do not make eye contact. Her advice was to send him to a kindergarten for 'normal' children and not to tell them of the diagnosis. The parents asked whether there were any centres with autism specialists, mentioning the Amira Basma Centre in Jerusalem that they had heard of. However, the supervisor told them that the Amira Basma Centre, as they would know, would be very difficult for them to get to because of the travel restrictions. She also told them that the Amira Basma Centre only dealt with physical disabilities. Presumably she did not know that they had a newly-opened early-years centre for autism. (FN 3/12)</p>

Table 10: Extract from field notes (3/12)

This extract is not chosen to highlight what might be perceived as shortcomings of its protagonists, quite the reverse. Shining through all the challenges here, are heroic efforts of parents, people in the community and dedicated professionals, working hard to support and provide for children with autism in Palestine. This illustrates many of the subordinate themes within Theme A: the difficulties of obtaining a



reliable diagnosis; the lack of support and guidance for parents; social attitudes that prevent parents from being open about the nature of their child's difficulties and, in this instance, resulted in the professional advice to keep quiet about the diagnosis; the poverty of resources for autism and the unsustainability of donor funding; the lack of training and knowledge of people best placed to be able to help; and yet, in this instance, there seemed to be an intuitive grasp of some of the fundamentals of good autism practice: the need to work with parents, the need to think about the child as an individual and tailor individual approaches. There was a hint, though, in the centre's policy to only take 'good' children that parents of autistic children with greater challenges may have difficulty in accessing a community provision such as this one.

As with Ahmad's parents, a perplexing isolation dominated the lives of many of the parents I met or who were described to me. This is a powerful theme in a moving study by Dababnah & Parish (2013), which describes a toxic mixture of stress, shame and blame that is the experience of parents of children with autism. Yet there were parents I met and heard of who had strong signs of agency: some parents such as Dima (P1) had sought out other parents and formed a group; many others such as J (P2) had scoured the internet for advice and information; one father of a teenager with autism was engaged in a study to research the experience of parents; others I was told of had given up trying to raise a child with autism in Palestine and gone abroad. So the parents I met certainly faced challenges but it would be a mistake to portray them as mere victims. In this respect my data differs from that of Dababnah & Parish but it is likely, I suggest, that this is due to the fact that most of the parents I met had found suitable provision for their children. It is fair to say that the parents I

met, mostly drawn from the two pioneering educational centres involved in my case study, formed an unrepresentative sample and I would accept that Dababnah & Parish's depiction of families with autistic children in the West Bank is likely to be more typical than mine. However it is constructive to look at exceptions and see the possibility of doing things differently. I was told of, but did not meet, parents who survived the challenge of autism by tying their child up or locking him away from the eyes of neighbours, as I describe below in the section on social attitudes, so I do not doubt that there is considerable suffering for many families. Although beyond the scope of my research, undoubtedly there are socio-economic factors at play; there is considerable poverty in Palestine and families with more income and higher levels of education are better placed than more disadvantaged families to overcome the challenges of having a child with autism.

Even so, despite my highly selective sample, challenges for parents and families was a potent theme to emerge from the interviews. Four parents spoke of a negative impact on families of having a child with autism. One mother wept as she told me *'Nobody knew we were having this crisis. We were having a terrible time with our daily life because Sami couldn't enter a supermarket, he couldn't enter a shop, he couldn't enter a restaurant'* (P2). In one case the mother (P1) said that her friend, the mother of another child with autism, had moved to Norway in search of better provision for her child. Another mother (P2) spoke of the financial cost and said that *'It has been a lot of time, effort and money to help'* her son. One mother found her own freedom had been curtailed because of the lack of acceptance by family and neighbours and that *'because of that I prefer to stay at home with her all the time'* (P5). For one mother (P3) the importance of finding an inclusive setting for her son

meant that, even though she lived in Jerusalem, she made the gruelling and humiliating journey through Qalandia checkpoint four times a day so that her son could attend Friends School.

Parents gave voice to both negative and positive feelings about their child's autism. One parent said that she was depressed and *'didn't want my child to be autistic so I tried to teach her to look normal.'* She feared *'I will lose my child'* (P4). Another mother also spoke of depression and said that she feared for her son's future, saying *'I am not happy because I will die and he will stay alone in his life'* (P1). A father said that when they received the diagnosis *'We were in shock'* (P6), and another parent spoke of a *'crisis'* in which *'there was denial and I was crying all the time because all my dreams they were smashed'* (P2). However, in all cases the parents also spoke about the journey they had made in coming to accept and love their child and the growth of more positive feeling about him or her. *'He is amazing. He is a gift'*, said one (P3). *'I'm lucky to have him ..... he changed our life, he changed me for the better'*, said another (P2). A third mother said that she was *'hopeful for the future, inshallah'* (P5).

In thinking about the impact of autism on families it is important to consider the impact on siblings. Dababnah & Parish found that female siblings often shouldered caregiving responsibilities and this was born out by a parent interviewee who, speaking of her son, told me *'his sister will take care of him when he is older'*. Another impact on siblings was pointed out by one community provider who reported that *'there is a problem if they have other children because nobody will want to marry them because this family has disability so if you marry into this family [people think] you will have a child like him'* (CP1), so the future well-being, happiness and social

inclusion of siblings was also thought to be affected by the presence of autism in a family.

Three parents chose to talk about the negative impact of the occupation on their lives. Having a baby at the time of the second intifada was an anxious and unsettling experience for two mothers (P1, P2) and in one case (P2) the mother experienced dangerous difficulty in getting through the checkpoint to reach the hospital in Jerusalem when she went into labour. One of the parents (P4) who lives in the West Bank and attends the Amira Basma Centre, is only able to do so because of the special arrangement that the Amira Basma Centre makes for West Bank parents to attend for a three week residential stay with their child, followed up by occasional further residential visits. Travel restrictions for Palestinians living in the West Bank seriously limit their ability to access facilities outside. Commenting on the difference between facilities for Palestinians from those that are available for Israelis, one mother said that she looked at a Centre (not the Amira Basma Centre) for her son in East Jerusalem and that it was, *'Horrible – not like the centres they offer for Israelis. There are much poorer services for Arabs. Of course, it's the occupation'*

Parents and families are important for all children but in the international world of autism they are the ones who have led the way in making the world a better place for children with autism. So often it is the parents who see the child's strengths as well as their difficulties and who find out what works for their child. This notion came through in the interviews with parents and it was compelling to hear about their individual children. The profile of children with autism can vary very much from one to another and just from talking to this very small sample of parents it was clear that the six children were all very different, despite the similarities due to their autism.

Interestingly, the parents did not confine themselves to describing their children in terms of deficits and difficulties. Table 11 gives examples of the things that parents said about their children and I have placed their comments into three groups: strengths, difficulties, likes/dislikes.

Strengths		Difficulties		Likes/dislikes	
Good visual strengths	P1	Hates changes in the environment	P1	He likes the computer	P1
Drawing	P1	Doesn't understand the meaning of a game	P1	He really dislikes teddy bears	P1
Many strengths	P2	Doesn't like surprises	P2	She likes to spin everything	P5
Complicated jigsaw puzzles	P2	Doesn't understand danger	P2	He loves technology	P3
Responds well to structure	P5	Doesn't talk	P5	He loves school	P3
Brilliant memory	P3	Doesn't understand explanations	P3	He loves English	P2
Aware of feelings of others	P3	Sits in the corner alone	P6	He has started to make symbolic play	P6
Wakes up smiling	P3	Distressed when we cut his nails	P6	Spinning was fascinating for him	P2
More disciplined than brother	P6	Sleep problems	P2		

Table 11: What parents said about their children with autism – some examples.

These parents were good observers of their children and their knowledge of their child enabled them to identify the approaches to help them to develop and progress. Examples are given in Table 12.

Approaches that work for my child	Interviewee
I find out what he loves. I teach Karim what I want to teach him but in his way: in straight lines, in singing, in his way, not the standard way.	P1
I have to talk to him in simple words.	P2
The best strategy is to explain things to him. I tell him what we are doing and why we are doing it. I explain what we are doing.	P2
I have to make it dramatic. It helped him. By making it dramatic, it pulled his concentration to me.	P3
He doesn't always realise that he should be listening to the teacher. We need to say his name to cue him in.	P3

Table 12: Parents identify approaches that work for their child – some examples

This points to parents as an invaluable resource when thinking about the needs of children with autism and in Palestine where resources are limited, they are surely a resource that can be tapped into freely.

## Theme B: Diagnosis

I was told the story of a mother who was concerned that her four year old child, Yousef, was not talking and did not play with his siblings. She saw a paediatrician who took Yousef into his office for fifteen minutes after which he returned Yousef to the mother, gave her a sealed envelope and moved on to the next patient. The mother opened the envelope and read *'Your son is mentally retarded and should start a programme with us'*. No further advice was offered. Two years later the boy was diagnosed with autism. This story was told to me during an interview (U1) with a university professor, very active in the field of autism in Palestine, to illustrate the lack of knowledge of the medical profession and the resulting anguish for parents.

The issue of diagnosis was raised frequently during my research. As with my previous example of Ahmad's parents, above, the lack of reliable diagnosis was a source of distress for many interviewees who spoke of the lack of good or timely diagnosis in Palestine (Table 13).

Comments	Interviewee
[There is] no opportunity for proper diagnosis within Palestine.	M1
I have not until now [I have never] received a formal diagnosis in the West Bank from a reliable source. I say this with full confidence.	T1
In our country it is not possible to find specialists. They are not well qualified. They don't know how to identify a child's strengths and needs.	CP3
[Good diagnosis is problematic] in everything, but more with autism.	PR1
There is a lot of confusion between intellectual handicap and autism.	M2
Children with autism are not identified as such and may be thought to have a mental disability or a behavioural difficulty.	M1
Often there is a lot of confusion... and they are diagnosed as ADHD and they put them on Ritalin rather than realising that there is a problem with communication or social interaction.	T1
Diagnosis [if it occurs] is likely to be when the child is 6 or 7 which is not soon enough.	CP1

Table 13: Comments describing problems with diagnosis

One interviewee (U1) had challenged the Palestinian Bureau of statistics as to why they had no category for autism in their reporting of the incidence of disability. He asked '*why don't we have autism as a category? They answered, and they are right, because we don't have diagnosis*' (U1).

I found that there was a disparity between experiences of those parents living in the West Bank (P1. P2. P3) and those living in East Jerusalem (P4, P5, P6). Parents

from the West Bank spoke of the frustration of visiting doctors and paediatricians who were not able to give diagnoses or clear advice. Two of the three West Bank parents were eventually able to have diagnoses from doctors in East Jerusalem and the third found a French doctor in Bethlehem.

It was not only parents who found the lack of diagnosis frustrating. A member of the special needs team at the Ministry felt that without diagnosis there could be no provision for the child with autism:

*We first need to identify the people who have autism by reliable diagnosis .... The next step is then to ask: how can [we] help them and what is the best provision for them (M1).*

As well as the heartache for parents and the lack of guidance for professionals, each caused by lack of reliable diagnosis, several of the interviewees expressed disapproval of the frequency with which medication is given to children with autism or with behaviours that may relate to autism:

*The families didn't know what to do so they go to the neuro-paediatrician and they give them Ritalin, most of them (PR1).*

*The doctors give the child medicine such as Ritalin to be calm, to be not active. I think this is a problem. They give them medicine to sleep or to be quiet. And there is no intervention for autism (CP1).*

*Giving a lot of medication will be an obstacle to our behavioural diagnosis for children. This is really a big obstacle for us (U1).*

Parental pressure was seen as a possible factor by one of the interviewees who reported a paediatrician as telling him that:

*Sometimes I don't want to give medicine but the parents insist. [They say] 'If you don't give medicine then you're a stupid doctor'. They want to see their child more calm, sleeping, but this is not the solution (U1).*



Parental pursuit of medical solutions as an answer to the challenge of autism was also indicated elsewhere in my data. Having seen and admired the worthwhile work of one centre I visited (described below) I was told that they refer parents, those who can afford it, to the Total Wellness Clinic in Jordan for treatment and advice.

One interviewee talked about how parents go 'shopping' for a diagnosis, saying:

*It is a market in Palestine..... They [parents] pay something like 1,500 shekels, about £300. They get a piece of paper saying 'your child is autistic'..... The other problem is that the people who see the child never write a report..... sometimes 30 people have seen him..... They [the parents] go around, around. OK if I don't like you I will go there. So it is like shopping (U1).*

A number of interviewees spoke authoritatively about their ideas relating to how diagnosis should be carried out.

*We know that there should be a team approach but we do not have teams here (SP1).*

*We need to observe him in his community... We need to observe him in his community [and there should be] no diagnosis before giving the child at least six months of time for observation (U1).*

*Diagnosis is undergoing a process of therapy. I know if I am going to start with the child I need to finish with him. I'm not somebody who is selling cigarettes. The diagnosis is something that helps us to build intervention. Not to put the child under a category (U1).*

Interestingly, one of the interviewees spoke about the work that he has done to develop a screening tool for autism, the Basha Behavioural Autism Spectrum Disorders Screening Test (BAT), which has introduced a diagnostic instrument for autism in the Palestinian Territories for the first time.

*The BAT is born from long reflection on ICD10 and consultation with international bodies and with 68 local university professors. We spent three years working on it. We had videos, like 140 hours of videos and observation,*

*just to add the items that should be observed in the screening test. We have tried it and done a lot of research and it is working (U1).*

The BAT has been developed as a kit, used in other countries, translated into English and is almost ready to be launched internationally. Dr Basha who has led this initiative said:

*We are here on a small piece of land in Palestine but we still think ourselves able to contribute something. .... It is our contribution on an international level.*

The BAT takes into account cultural differences that affect diagnosis. For example, Dr Basha felt that facial expression and gesture is a much more significant factor in communication in the Middle East than, as he suggested, in Scandinavian countries that he has visited. The BAT also takes into account cultural differences in the way it is designed to be used by the parents.

Findings on diagnosis point to widespread lack of identification of autism in Palestine.

### **Theme C: Social attitudes towards autism, special needs and disability**

‘ال توحّد’

The Arabic word for ‘autism’ is one that I grew very familiar with, although it contains consonant sounds that are unfamiliar to the European ear. What did the word ‘ال توحّد’ mean for Palestinians and would their concept of autism, like the guttural phonology, also be unfamiliar to me. Was autism accepted as a legitimate difference? Was it shameful or to be pitied? Would a person with autism be revered or shunned, feared or accepted?

To commemorate World Autism Day in April 2012 Palestine held its second national autism conference in Bethlehem, a lavish high-profile event attended, by my estimate, by 250 people. It was organised by the Special Education Department of Bethlehem's Ahliya University. After opening protocols there was a 40 minute 'theatrical play about autism'. An adult actor played the part of a child with autism, flapping hands and making random movements and vocalisations. It was the story of a family who, after a succession of girls, prayed for a boy. God gave them a boy but it was a boy with autism. Doctors were of no help and the mother kept the boy hidden from neighbours, pretending that he was OK. The family felt he was a punishment from God and the mother became a prisoner with him. Eventually a neighbour, having heard of autism, guessed the truth, confronted them and helped the parents to begin to see their son as a 'gift' from God rather than a 'punishment'. This play was a product of its own time and place. It clearly had a message about acceptance of difference and disability and it certainly resonated with stories that I had been told about children being hidden away and seen as a punishment from God, but it was interesting to reflect on the portrayal of a child with autism, perhaps a negative and grotesque parody of autism to European eyes. I can do no more than wonder how it was understood by the rest of the audience but I suspect there was a spectrum of responses. Indeed, my data relating to social attitudes towards autism, special needs and disability certainly presents a mixed picture, as I will show.

The perception that predominated in the interviews was that negative social attitudes towards autism, special needs and disability prevailed. Table 14 brings together some of the negative things that interviewees said about social attitudes:

<b>Interviewees reported negative social attitudes towards autism, special needs and disability</b>	<b>Interviewee</b>
We have some families they keep their children in a room in their house and they don't show them to others.	T2
We still don't have a very positive perspective. People in our community look at it as ...pity, pity you know. It's something more from the religious, charitable perspective you know... poor parents.	T1
Social stigma related to autism in general is not very positive and it is really hard for the parents, very hard for people to understand what it means. They really relate it more to a mental issue. Sometimes they're even afraid to talk about it.	T1
The children are sometimes left isolated at home.	CP1
At parties like Eid when their families come and visit them they put him [the child with autism] in a room and close the door. They don't let anybody know and they may hit him not to make a noise.	CP1
The mother says why has this child come to us? What have we done to have this child? They don't want the neighbours to know that they have the child. They hide it in a room. They look for residential centres to send the child away.	CP1
They discovered a child in Betunia, he's 23 and he was tied in the place with the sheep. There are many stories like this in the villages near Hebron, and north of Nablus, many of them. Children with autism have a real problem in Palestine.	CP1
My cousin moved to the US because his father didn't want the people around him to say that your child has autism.	CP2
Some parents have a problem. They want to hide and they refuse to accept that their child has autism.	CP2
[Parents have negative attitude] because they are the victims of wrong education in the past.	U1
When he [the child with autism] couldn't draw or write she [the mother] would become very tense, she would even threaten him with the slipper.	T1
We are now developing our work to deal more with those children [children with 'cognitive problems'] because usually they get out of the schools and become the criminals in the streets later on in life so this is very important part of our work.	T5
The doctor told her [a parent], for her 14 years child that she should have her child's uterus removed. He said she's never going to marry but she might face sexual violence and I am afraid she might get pregnant .	U1

Table 14: Negative social attitudes towards autism, special needs and disability

Negative social responses were also reflected by parents. Whilst three of the parents said that their own families were accepting of their child (P4, P3, P1), one mother

said *'My husband's family does not accept the child. They shout at her'* (P5); another said *'The neighbours' children won't play with Samar. She goes to them and they go away'* (P4). Another parent said that her family and neighbours *'started to say what is wrong with Mahmoud? He is stupid, he doesn't understand'* (P6); whereas yet another mother was herself *'blamed'* for her child's differences when she found that *'People made comments that I am a bad mother for not having a good child'* (P2).

I was told that *'people think it is a waste of money to spend it on these children'* (CP1). One parent said that because her son has autism *'some teachers think he is a waste of time'* (P2). The negative view of autism had also led others to suggest that it was wasteful to devote resources and money to children with autism. A leading official in the special needs section at the MOEHE reported that:

When we signed the agreement for the 36 resource rooms..... I had the Minister saying, 'what are you doing, we will have people on the telephone, and on the TV and radio saying we are opening [school places] for mentally [retarded], for the idiots' (M2).

However, some of the interviewees raised a note of optimism and spoke of changing attitudes and greater acceptance of difference, as evidenced below (Table 15).

Changing social attitudes	Interviewee
There seems to be a growing acceptance of disability and SEN although this is not the case throughout society. Attitudes are changing.	M1
The child with disabilities is more and more accepted in schools, in communities, at home. It is not a shame any more.	T5
Autism, there is an awareness nowadays in the media. It is talked a lot about. It's more common. It's [now perceived that it is] not the parents' fault. There is general awareness in the Arab media as well. Nowadays with the satellite you get all channels so people are interested.	T1

When I first came it was very difficult to get parents to agree that their kids with disabilities could go to government schools. The parents thought that the other kids would laugh at them. Parents of children with visual impairment wanted them to go to special school, but things are changing. There are many success stories.	M2
Now we have a big difference than the past. Now they are accepted of course. Maybe not all, but most are accepted because they are more aware about special needs. Before marriage they have to do some blood tests to see whether they can get married or not.	T2

Table 15: Changing social attitudes

Two people expressed the view that children in their schools were positive towards children with different and additional needs.

*They [peers in school] love the [children with special needs] and they help the children with special needs and some children with special needs become better than the normal children (T4)*

*Their [the children's] attitudes are much better than the adults. There is more acceptance (of special needs) between the children. In every school we have a committee of friends (of the disabled). They help their colleagues (M2).*

A number of interviewees talked in terms of the rights of people with disabilities, learning difficulties and autism:

*As Palestinians we have learnt to fight for our rights and now we are fighting for the rights of people with disabilities (M2).*

*People are recognising more that these people are people, humans. They should have equal opportunities and they are asking for their rights, fighting for their rights. There are many institutions and foreign institutions that are supporting these people who are supporting people with disabilities or learning difficulties (T3).*

*It is unique to have a human rights worker in a centre with disabled people. I have written several articles on the Internet about the children here, about their right to education and about the problem of autism in Palestine (CP1).*

*Every student should take his rights [is entitled to his rights] and social equality (T4).*

One person talked about the greater acceptance of physical disability, compared with other types of disability or difference:

*In Palestinian society for PD [physical disability] [there is] now no problem because through the two intifadas we have many injuries – spinal and so on, so it's like a hero [if you have a physical disability you are thought to be a hero].... But with intellectual disability and with autism there is not enough awareness, especially about autism. Some of the people are dealing with them as mentally retarded. When you go to the restaurant with your child with autism others are looking at the mother like she didn't know how to raise her child (PR1).*

Again, as with diagnosis and provision for children with autism, there were suggestions that social attitudes differ between regions:

*Maybe in the Ramallah area it [attitudes towards autism] is better but in the villages north and south it is a problem (CP1).*

*In the villages where people are much more simple, they look at these things like shame..... so hide him away, exclude him, isolate him [whereas] Ramallah is much more intellectual and educated and they are more accepting (P3).*

Data suggest a changing climate of opinion towards conditions such as autism in Palestine. Conditions such as autism continue to be stigmatised but there is a shift towards greater acceptance.

#### **Theme D: Special or Additional Needs and Disability in Palestine**

The data here relate to policies, provision and practices in relation to special educational needs in Palestine. One interview provided a useful historical perspective to the development of SEN provision in Palestine, information that I had not found in the literature, and showed what been achieved in a short space of time and in challenging circumstances. In 1995 a Special Needs department was started single-handedly within the Ministry of Education by one person who came with knowledge and experienced gained in Jordan and it was stirring to hear her first-hand account of this.

*Before that nothing existed because it was under Israeli occupation. There was nothing at school or government level regarding special education. It was not easy to start alone, to plan, to implement in the West Bank and Gaza. There was nobody to help you (M2).*

This paragraph is a summary of information from this interview (M2) about the development of SEN. Nobody had previously addressed the issue of children with special needs in schools, but with support from UNESCO and international donors such as Diakonia / NAD and Save the Children, developments towards IE for children with special needs were beginning to take root by 1997 and by 1999, Palestine had become a signatory to the UNESCO 'Education for All' initiative and 36 teachers were trained to become Inclusive Education Counsellors (IECs) whose role it was to support schools to be able to include children with SEN. Since 2004 Resource Rooms were opened in thirty six schools in Palestine (West Bank and East Jerusalem) with the support of the Swedish Organisation for International Relief, to offer withdrawal support to children with SEN. In every school there is one teacher, or in larger schools two, with the role of supporting pupils with SEN and to enable them to fulfil this role they have received 36 hours training, although it has not been possible for these teachers to have a reduced workload and so their ability to be effective in their role is limited. In addition to the 36 Resource Rooms<sup>18</sup>, there are also three Resource Centres, in Ramallah, Hebron and one in Gaza. These centres are staffed by multi-disciplinary teams of five specialists in each centre: physiotherapists, occupational therapists, speech therapists, special education and social workers and their workloads are huge. The Ministry of Education categorises

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<sup>18</sup> The number of Resources Rooms in WB and East Jerusalem has now risen to 108 (personal correspondence 24.3.15)



disabilities in the following way: physical disability, hearing impairment, blindness, mental handicap and Downs syndrome.



Figure 22: Resource Room, Faisal Hussein School, Ramallah.

Other interviewees expressed doubt that schools and teachers had the knowledge and capacity to meet the needs of children with SEN:

*Many schools, do not accept children, [because] they are not able to provide educational help for that child as the child's needs are [beyond] the capacity of the school (T1).*

*[The child with autism] will not benefit much from kindergarten as they will not have special programmes (CP3).*

One interviewee felt that 'We need to change the mentality of teachers' (T3).

However, it was claimed that progress was being made by the schools run by the Ministry:

*There is a really good interest from the Ministry of Education, from the special education sector..... in our governmental schools we now have people who are observing if any child is different (U1).*

One interviewee felt strongly that there were some institutions (not amongst the places I visited), that served children with special needs very badly, especially those with a charitable or religious mission:

*Disability and autism is a serious business. It's not [to show] that you are a good person, that you have charity on people. It's not enough. Forget about it. Go and pray by yourself. They are really hurting the children (U1).*

There is an overlap between this section and the next where I look more specifically at autism provision. Some centres that I describe in the following section are, in the first instance, set up for a wide range of children with special needs, not just autism.

As will become clearer in the analysis of data set 2 (section 6.2) there is little evidence to suggest that any more than a very small number of children with autism are catered for in Palestine's schools.

### **Theme E: Autism provision and practice in Palestine**

**'A step towards autism is a step towards humanity'.**

(Tagline from the mission statement of the now-defunct Palestine Coalition for Autism)

I visited a number of centres for children with special needs and some of these included children with autism. I write about these before discussing data from the interviews relating to practice and provision. My visits gave a picture of what is available but it is just a snapshot and I am aware that there are other centres such as those in Jenin, Hebron, Ramallah and so on where I would have loved to have to opportunity to visit.

The Annahda Womens' Centre in Ramallah is an impressive, well-established centre which has five classes for its 45 children aged 6 to 20 who have 'mental handicaps', and staff also do outreach work with schools. Although they do not specifically cater

for children with autism they have sought to inform themselves about autism and have identified some children in the centre whom they think have autism. It is a matter of principle with them that they work closely with parents and that all children are assessed and their progress monitored through individual education plans. One of their challenges is that parents sometimes default on the fees that they should pay but the centre hasn't the heart to then reject the child. The centre cannot meet the demand for places and has to turn children away. They would like the Ministry of Education and the Ministry of Social Affairs to support them financially but this has not happened. The centre is sensitive to the needs of young people above school age and has introduced a thriving sheltered workshop to make and sell wooden toys and other artefacts. Staff here, as with staff at the Friends of Autistic Children Society above (Table 10, p.123), also said that no centres will accept children who are perceived to be problematic, such as those who are unable to communicate or who are hyperactive (FN 15.10.11).

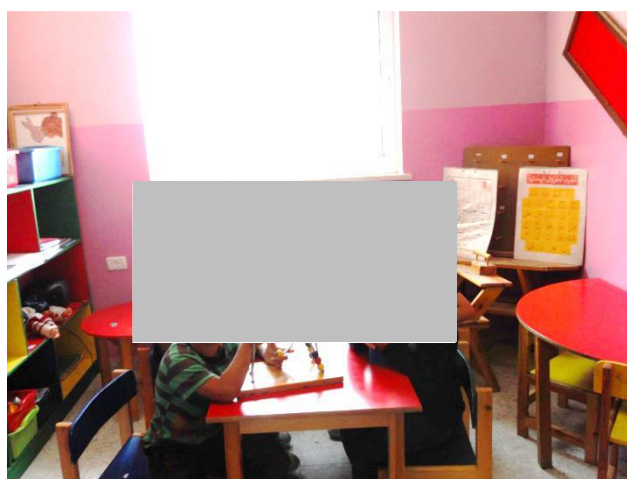


Figure 23: Annahda Women's Centre, Ramallah

Another centre, Friends of Autistic Children Society had recently moved to a new building in Al Bireh, near to Ramallah, when I visited. It was set up by parents specifically for children with autism and currently has eleven children aged 4 to 12. Again, they cannot meet the demand for places and have to turn children away. Parents are closely involved and children are assessed, monitored and given individual education plans. Although staff have not been trained to work with autism, they have looked on the Internet for guidance. The Society employs a speech and language therapist to work alongside the two teachers. The management team have well thought out ambitions for the Society including the development of an 'autism village' with a diagnostic centre, early intervention programmes, research related to autism, a day centre and clubs for children and adults with autism, education, medical support and therapy including a therapeutic animal reserve. They had a vision of exchange visits with the UK for practitioners, training programme of high quality, training materials for parents and they proposed a link between University of Birmingham and the West Bank to provide training for professionals. They wanted to develop this but have no funds; they too lamented that financial support is not forthcoming from government departments (FN. 18.4.13).



Figure 24: Friends of Autistic Children Society, Al Bireh

The Star Mountain Centre in Surda is a well-managed non-profit community resource that caters for 75 'intellectually disabled persons' aged three to 40 coming from eleven villages and one refugee camp. Their work is partially funded by overseas donors and it is a constant struggle to balance the books. There is a fee for students but where parents cannot pay they sometimes contribute by giving olive oil or by working in the kitchens. Recently, in response to demand, the Centre introduced a special group for six autistic children who also have learning difficulties and staff have sought to develop their skills in this field, working closely with parents and placing an emphasis on building strong relationships with the children. They use IEPs to promote the children's independence, emotional well-being, language and social skills, basic cognitive abilities and physical skills. They also seek to adapt behaviour and their work is supported by a broad creative programme. They felt they had achieved some success in enabling the children to develop useful life skills but acknowledged that the teachers working with these children had the greatest challenge of any in the Centre (FN. 6.11.12).

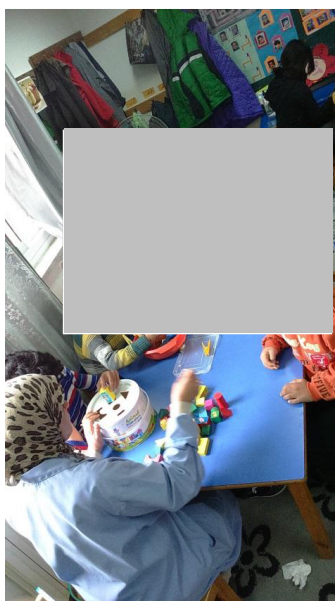


Figure 25: Star Mountain Centre, Surda

I met two dynamic young men from Jerusalem Autistic Child Care Organisation (JACCO), a group of professionals with a strong interest and a background in autism education. They do not run a centre for children to attend but rather they work to support the inclusion of children with autism in the voluntary sector and in schools by doing outreach work in schools and training professionals, volunteers and parents. They are committed to working to overcome what they see as Palestine's misapprehensions about autism (FN. 4.13).



Figure 26: JACCO  
Jerusalem Autistic Child Care Organisation – workshop

Tulkarem, in the north of the West Bank, has a rehabilitation centre for children with disabilities and my visit came not long after they had set up a group for children with autism in a small cramped room with tables and chairs, papers and crayons but, as far as I could observe, that was all. The two warm, kindly women running the group were poorly paid and untrained but coping as best they could with a diverse group of eight children aged 3 to 12. I had come there with two participants from the Amira Basma Centre on their outreach programme to help people in the West Bank to work with autism. They were trying to get staff to introduce visual schedules and feeling frustrated that they were still not in place. On their previous visit they had gone out with their own money and bought toys for the children to play with. This had the

appearance of being a much more economically deprived area and staff said that parents were glad of the respite the centre gave them but were not keen to be involved. The play area looked out through metal bars to the street beyond and was under-resourced (FN. 23.4.13).



Figure 27: Tulkarem Rehabilitation Centre

The Autism Unit at the Amira Basma Centre (ABC) in East Jerusalem is unique within Palestine. ABC is a charitable medical centre for children with disabilities, serving families throughout Palestine although, in reality, it is very difficult for families in the West Bank and all but impossible for families from Gaza to get there because of the draconian travel restrictions. It is one of the two centres involved in my case study and I will introduce it more fully in Chapter 7. I mention it here because I feel it is an important part of the contextual picture that I am sketching out here and stands as a beacon of good practice. Again it is a non-profit-making venture, but staff have been trained in approaches for working with children with autism, they are well-resourced, with specialist facilities and funding is more secure than that of its West Bank neighbours. A multi-disciplinary staff includes teachers, speech and language



therapist and an occupational therapist and they are experiencing considerable success through offering an enabling environment and autism-friendly approaches. In the picture below, in the naturalistic setting of snack time, staff are seeking to build strong relationships between themselves and the children and between the children and each other and they are using visual cues to promote and support communication. Staff are keen to share their newly acquired knowledge and understanding with less fortunate fellow Palestinians in the West Bank and have undertaken a programme of outreach work with centres there.

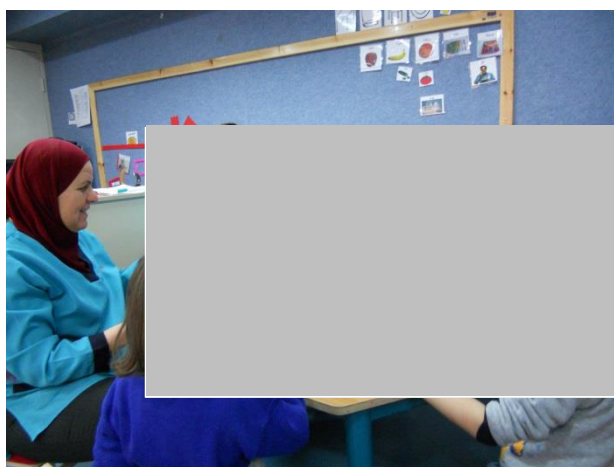


Figure 28: Amira Basma Centre Autism Unit

This handful of vignettes offers a partial answer to my research question about practice provision for autism in Palestine. Taken together it shows that there are motivated communities striving in difficult circumstances to make a better life for Palestine's autistic children. Some years ago, a number of organisations, including some of those here, banded together to form the Palestine Coalition for Autism. Sadly it became inactive for lack of funding and the impossibility of growth. The stalwarts are still there, I met some of them. They started out with a noble vision of



what they hoped to achieve and the belief that 'a step towards autism is a step towards humanity' but that vision may have become blurred.

Almost 70% of interviewees (13) gave the opinion that Palestine was not yet able to address the needs of children with autism (Table 16).

Comment	Interviewee
Autism is a 'new area' in Palestine and is not widely understood by professionals or within society as a whole.	M1
We are not ready to work with children on the autistic spectrum. I think we need that.	M2
We don't feel that we are capable of assessing children on the spectrum.	M2
We are aware that they have minimal knowledge in that field. Some (IECs) do their own reading.	M2
They (IECs) have only a limited understanding of the autism spectrum and the interventions that could support these children in schools.	M1
People who know about autism are rare in Palestine.	M1
I think we need training.	T3
There are a lot of people who are trying to work with autistic children and unfortunately we don't know if they are doing it right or wrong.	T5
Even the most supportive teachers at sometimes [might say] 'my god, he's so spoilt'.	T1
I feel that they (Ministry of Education) are a bit hesitant, frightened let's say. They are not. I don't think they actually believe that a child on the autistic spectrum can be part of a school.	T1
I don't have a good background in autism. I don't know how to organise for these children or how to know or doubt that the child has autism. Also the staff here don't know so they need some training and workshops to help them.	T4
We have a big problem in Palestine because there is no good understanding of what autism is and we often do not distinguish between people with autism and those with mental disabilities.	CP1
People are not qualified.	CP2
One of the main obstacles I faced was that I had nobody to refer to, nobody to discuss with and share my experience at school.	T1
They touch your heart. I work with different disabilities but those children [the ones with autism] they touch your heart.....Sometimes when I am praying I pray god will	PR1

help me to help them. Give me a way to help more.	
I have met parents who have had their children staying in institutions for ten years and they have nothing, no data. They are babysitting the child.	U1
Nobody knows about autism.	P2
Unfortunately in the West Bank we don't have centres or programmes (for autism). The Palestinian curriculum is a disaster for him.	P3
The problem is that the teachers in the schools do not know how to deal with autistic children. The government school won't take my child.	P5

Table 16: Comments to illustrate undeveloped support for children with autism.

One interviewee described the challenge of trying to include a child with autism in school:

*We had two kids on the autism spectrum but they were not able to communicate in class. The kids do not stay all the time in the resource room and when they went to the regular classroom they distracted other kids. They made noises and movements that affected others. We told the parents that we will take your children as an experiment because we are not ready yet to work with your children. One of the children left because his father thought he did not benefit from being in school. The other one is still in school (M2).*

One interviewee felt that 'most of the kids on the autistic spectrum are in special institutions' (M2), alongside children with a range of other disabilities. This thought was echoed by another interviewee:

*There is a centre in Nablus and it's not mainly for autism. They have hearing impaired children; they have learning disabilities like Downs syndrome and other mentally retarded children. This is not good (PR1).*

It was suggested that special needs centres would be reluctant to accept children with challenging behaviours and therefore not all children would have the possibility of a placement:

*We cannot cater for all the children who want to come here. If a mother comes to me and asks for help with a child of three or four years with autism who has*

*no abilities to communicate or is hyperactive, this is a problem. No centres will take him (SP1).*

It was also noted that there is a lack of post-16 provision: *'Provision for young people above school age is a problem' (SP1).*

A lack of understanding of the breadth of the autism spectrum was raised by a number of interviewees:

*In the West Bank if you have someone with high functioning autism nobody considers him as having autism (PR1).*

*I'm 100% sure that there are children on the autistic spectrum in government schools. And sometimes the teachers, or even the so-called specialists, are not even aware that they are within the autistic spectrum (T1).*

*Also we don't know about gifted autism (SP1).*

Again, as with diagnosis, there seemed to be regional differences between the West Bank and East Jerusalem in the provision for children with autism:

*And sadly to say there is no place suitable for autism in the WB. In Jerusalem, for the Arabs who live in East Jerusalem they have many choices in Jerusalem because they have Israeli ID (PR1).*

Professionals I interviewed were aware of the challenges faced by parents of children with autism (Table 17).

Challenges faced by parents (comments by professionals)	Interviewee
The mother with the autistic child if you give her the choice to find a setting for him or to eat, she will have the first choice.	PR1
One of the mothers from the WB told me 'I didn't go anywhere with my child, even to my family, because he is so hyperactive and making troubles so she prefer to stay at home. If I put myself on her chair [in her place] I would do the same.	PR1
It is so hard for them [mothers of children with autism].	PR2

Some of the mothers say that he beats me or he is shouting.	PR2
There are a lot of autistic children there [in the refugee camps] and no setting for them.	PR1

Table 17: Challenges faced by parents

Parents themselves expressed frustration at the lack of support and understanding from government bodies and from school staff in the West Bank and in East Jerusalem (Table18).

<b>Lack of support for parents</b>	<b>Interviewee</b>
There are no centres or programmes in the West Bank.	P3
Nobody knows about autism.	P2
Some teachers are not interested and think he is a waste of time.	P2
The government school won't take this child.	P5
The problem is that the teachers in the schools do not know how to deal with autistic children.	P4
The Palestinian curriculum is a disaster for him.	P3
Even in Jerusalem, the best school with a good reputation does not have a programme for kids with additional needs.	P3

Table 18: Lack of support for parents

Five of the six parents, in the absence of support and advice, had turned to the Internet for advice. Parents valued support gained from each other and for one parent (P1) this resulted in her working with other parents to set up a parents' association. Three parents (P4, P5, P6) whose children were supported at Amira Basma Centre all spoke of the value they attached to contact between parents encouraged by the Centre (Table 19).

Parents support each other	Interviewee
It is good to meet with other parents because we help each other.	P4
We feel that all of us are a family.	P6
When I met the other parents I could take more information from them. We can talk about how to deal with things. We can support each other because we have the same problems.	P5

Table 19: Parents support each other

It was felt that lack of understanding about autism resulted in inappropriate or abusive treatment:

*They are treated as naughty children, ADHD or intellectually challenged, or developmental delay, or speech and language (T1).*

*Or tied because he is so hyperactive and destroys everything in the house. It's like a dog, yes (PR1).*

Many interviewees spoke of a shift in the climate of opinion:

*Now, there is a lot of interest in autism in Palestine (T1).*

*We have to start somewhere; we have to do something (U1).*

Visits to the centres, sketched above, showed on-going endeavours to address the needs of children with autism, a growing field of interest in Palestine.

## Theme F: Inclusion

Data suggest that the notion of inclusion has strong currency in Palestine. People from different fields spoke fervently about the importance of inclusion, in terms of beliefs in social inclusion, equality or human rights (Table 20).

Support for inclusion and human rights	Interviewee
Children with autism are also children and must be included, or else it is as if the CRC [Convention on the Rights of the Child 1989] is just for normal children. Some articles	CP1

in the CRC relate to disabled children but all the articles should relate to <b>all</b> children so that they have equal rights. Human rights are for everyone. The human rights approach should be used in all workshops.	
I believe strongly that every student should have rights. He should learn in the society. I believe in social equality.	T4
We are working to include autistic children with normal students in the classroom.	CP2
[Autistic children] need to be social, to have friends.....to be included in society.	CP1
I don't only believe in educational inclusion. I believe also children have to be in school for social inclusion for their growth as a whole. And this cannot be provided by special schools.	T1
The other children accept them simply because they grow up together.	T3
We believe in equal opportunities for children. Not [privilege] for those who can pay and the poor people not. We believe in equal opportunities for children everywhere and without any discrimination – race, religion whatever.	PR1
The family likes [their child to be with typically developing children]. They brought their children here – because they have the chance to be with regular students.	PR2

Table 20: Support for inclusion

Three parents spoke passionately about the importance of having their child in an inclusive setting (Table 21)

Parents feelings about inclusion	Interviewee
I don't want to put him in a centre where all the kids are the same as him. When he's with normal kids he will behave more like normal kids and his behaviour is more settled.	P3
This was the most important event in my life that Yousef comes to this school and I thank [named member of staff] for this..... The school is very good for him.	P1
Don't think, 'Oh no this year I'll have Nader in my class!' You'll be lucky to have him.	P2

Table 21: Parents' feelings about inclusion

Ministry officials expressed some satisfaction about what had been achieved towards inclusion in schools, but recognised that there was still work to do and felt hampered by a lack of clarity about inclusion:

*In the evaluation of Ministry of Education work in '99 it was said that the Ministry had succeeded in changing attitudes towards disability and they had succeeded in including children with visual impairment and physical disability. But we still have a problem with including children with hearing impairment or mental disabilities (M2).*

*[There is] no clarity about the inclusion policy (M1).*

*All schools are now aware of the Inclusive Education policy. In every school there is one or two teachers [...] whose load is decreased so that they can coordinate and support the teachers (M2).*

*Schools have been made aware of the issue of inclusion but in reality the support is not yet in place to make this possible (M1).*

Other interviewees were of the opinion that many children were excluded from schools because of their differences:

*They have started having the programme of integrating in the government schools but still we have a lot to do (T3).*

*In Palestine we have a big big problem. Most of our children who have needs don't even have education possibilities to be part of a school (T1).*

One interviewee suggested progress towards inclusion is hampered because teachers and parents retain the idea that there should be more special schools:

*The main ideas of teachers and parents is that we need more centres, we need more special schools (T1).*

The question of what is meant by 'inclusion' was addressed by some of the interviewees and there was confusion between 'inclusion' and 'integration'. For one person inclusion meant *'the way you teach'* (T1); for another it meant we must *'find suitable conditions for the children with special needs in order to include them in the class'* (M1). Another person said, in the context of inclusion, *'Every student should learn the subject he or she loves'* (T4). Another interviewee, seeming to use 'inclusion' and 'integration' interchangeably, considered that *'If we are going to*

*integrate the children we need to train, not all the staff, but at least the resource teachers, the teachers who work with the disabled children one-to-one while they are in the classroom and I think the autistic children if they are integrated they will need resource teachers and so we have to train the resource teachers' (T5).* For one teacher, the inflexibility of education in Palestine was a huge barrier to be got over: *'Our system of education is very, very rigid and this in itself is a big obstacle towards inclusion' (T1).*

One interviewee expressed frustration with the lack of understanding of inclusion:

*It's very strange and funny in the sense that they are talking about inclusion and at the same time they are doing an integrated classic system. So the children with SEN go into these resource rooms and it is only for 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> graders. So those children attend those classes and I think they have recently extended it for the 4<sup>th</sup> grade in some schools only. So they attend this class ... basically they work on literacy and numeracy as well as certain skills. So it is not exactly an inclusive set-up and there's not a lot of work and partnership with the regular classroom teachers. The regular teachers prefer to send the children who are giving them trouble or who are not doing well to the resource room (T1).*

So although the idea of inclusion is welcomed in Palestine, and this corresponds to the findings in the literature (Opdal, 2001; Farrell, 2007; NAD, 2010), the data suggest that it is timely for there to be a reconceptualisation of inclusion. A rethinking of the meaning of inclusion for Palestine is taking place in East Jerusalem in an Inclusive Education Project funded by the Italian charitable trust, Terre des Hommes and supported by the Palestinian Ministry of Education. Under dynamic leadership the project works to promote inclusive values and build capacity of schools to be inclusive, moving away from an approach which saw inclusion as something that happens only in Resource Rooms.





Figure 29: Children's mural on a school wall in East Jerusalem

Social deprivation and daily oppression makes the team's work extremely challenging, but the smiling faces of the children in this mural with the golden dome of Haram al-Sharif and the wall of the old city, their city, behind them give a poignant image of resilience in defiance of harsh realities. Resilience is a counterbalance to the next theme: barriers.

#### **Theme G: Barriers to progress in the provision for children with autism**

Barriers were ubiquitous: I met them on the ground and heard about them in interviews and discussions. Although barriers to progress is perhaps the *sine qua non* for all the other dominant themes, it was not obstacles that were dwelt upon but the wish to build and look ahead. This aligned with my own wish to be forward looking rather than focussed on obstacles and stopped me making 'barriers' my opening or super-dominant theme, for although 'barriers to progress' is at the core of the dominant themes, rather than seeing it as the super-dominant theme, I view it as an underlying sub-theme to all the other dominant themes. It is the backdrop and, like the ugly separation wall that insidiously weaves its way through and around the occupied territories it is never far from view. To focus primarily on the obstacles risks

casting the people I met as victims and detracts from their triumph over those obstacles. I encountered this spirit of resilience wherever I went in Palestine.

Interview data relating to barriers to making provision for children with autism fell into five broad interlinked groups and the one that linked them all was that of difficulties related to the occupation. Figure 30 illustrates how the barriers relate to each other. As one of the interviewees put it: 'the whole system is the obstacle' (T1). I now look at the data related to each of these five areas.

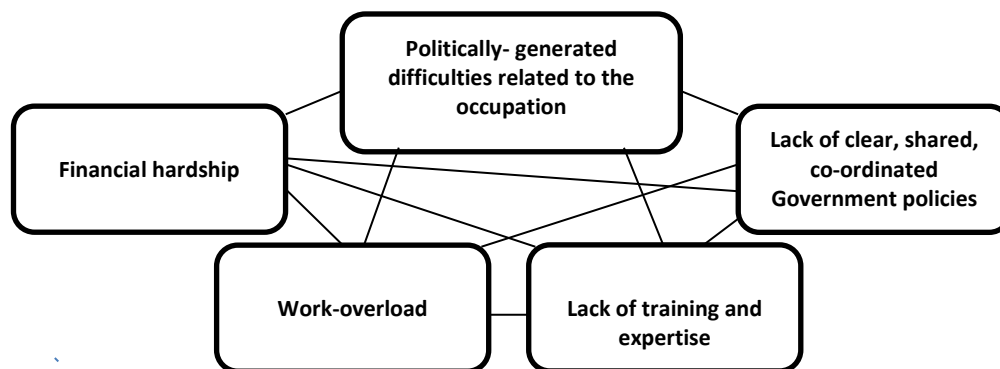


Figure 30: Inter-relationship of barriers

### **Politically-generated difficulties related to the occupation**

The prevailing conditions impacted on my research: twice during field work I had to cancel visits because of road closures; I could not travel to Gaza for security reasons; my translator could not always accompany me on visits outside Ramallah when she was unable to acquire a permit; I had to leave the conference in Bethlehem early, missing the slot for my short presentation, because my travel companion's permit was about to expire; travel restrictions made it enormously difficult to bring together the participants from the two centres in my case study. Several interviewees

talked of difficulties related to the occupation. From the early days of trying to set up special needs provision, just after the first intifada, there were restrictions of movement *'which meant that accessibility and moving around schools was very difficult'* (M2). Still a significant issue, the Amira Basma Centre in East Jerusalem is keen to support fellow Palestinians in the West Bank but:

*We live in a country where we have a problem every single minute – not just autism, not just poor. The occupation is a big challenge for us. If there is [were] no checkpoints between Jerusalem and the West Bank it would be easy for the people to come here, easy for us to transfer children.... They can't come to us because of the checkpoints* (PR1).

Talking of travel between the West Bank and East Jerusalem, one person said it was *'not easy because of their West Bank ID ..... they have to pretend they have a note from a doctor to come here.'* (PR1). The isolation of people in Gaza is even more severe: *'We used to get some [children at the Amira Basma Centre] from Gaza but not anymore'* (T5).

Time and energy is wasted: *'the checkpoints make problems because now we spend hours on the checkpoints'* (T2), and as well as the practical frustrations there is a damaging impact on society and on children:

*There are many causes behind the children being violent. First is what they live and what they see. It has to do with the political situation, I mean just going through a checkpoint makes them see the violence. It doesn't have to be violence by hitting. It's violent speech, verbal aggression* (T3).

In East Jerusalem the absence of self-determination for Palestinians is a barrier to developing one school's provision for children with autism:

*If we want to take children with autism we have to have permission from the Israeli Ministry of Education. They have not given us the permission yet. It is not very easy to [get] permission* (T4).

Another interviewee talks of a barrier to developing a Palestinian curriculum:

*If [the school] refuses to teach the Israeli curriculum, [the Israeli Ministry of Education] will not give them money. So the school goes to the Palestinian Ministry of Education and ask them about this problem [but] they can't give them money because there are a lot of schools here in Jerusalem. They can't [afford to] give each school money. The Palestinian Ministry of Education has very little [money] compared with the Israeli Ministry (T4).*

### Financial hardship

The lack of resources at the centres I visited was reflected in the interview data. MoEHE had to shelve plans to introduce a reduced workload for 'focus teachers' to enable them to have a role in supporting special needs, because of '*financial restrictions*' (M2), and they have been unable to develop this provision because they '*lack the resources*' (T1).

Centres outside the school system were also seen to lack funding (Table 22).

Lack of funding for centres in the community	interviewee
The problem is that we want to register this coalition. We need a place with faxes, telephones but we have no capacity for this. We search for funding. There is no funding, so the coalition is cold [inactive].	CP1
Unfortunately, no funds, we have financial problem.	CP3
In the West Bank there are some parents who began to make centres for their children but .... they have no funds. They need a teacher to work one-to-one. It is problem because you have to pay a lot and most of the children with autism or mental disability come from poor families.	CP1
All the centres they don't have money.	PR1
We have a problem with unemployment – the rate is very high. When a family has a disabled child there are no social workers. Maybe sometimes they give them some package of food as a help but that does not mean that they get their rights in life and their rights as a human being.	CP1

Table 22: Lack of funding for centres in the community

Interviewees spoke of the insecurity of relying on donor funding. Many of the centres that provide for children with special needs are dependent on donor funding from non-government organisations (NGOs). This can lead to instability as the donors may decide to reallocate funding elsewhere.

*This year the Swedish organisation in Palestine closed the centres in Ramallah area for the children with disabilities. This was because they decided to change from providing day care to advocacy (CP1).*

*There are sometimes projects that just last for a period but when the period is ended the situation goes back to what it was (CP1).*

Lack of financial resources has also limited the opportunity for Palestinians to be part of the international community and attend conferences related to autism: *'The money is the problem. If you want to go to the workshop or the conference, you have no money to pay expenses. We are not like Bahrain, for example, where the wives of the kings of Bahrain are members of the network [Arab Network for Autism]' (CP1).*

## **Work-overload**

Closely related to the issue of financial hardship, work overload was also seen as a barrier to meeting needs of children with autism. This was perceived as a problem at all levels. Firstly for teachers:

*Teachers often feel that they are unable to meet the needs of children with SEN because, as well as a lack of training, they have 27 classes each week and feel that they do not have time to teach children with SEN or autism (M1).*

*The focus teachers [appointed to support special needs in schools] are responsible for coordinating between the school and the Inclusive Education Counsellors [Ministry outreach workers for special needs], but they don't have any extra time to do this. They [only] help us with statistics and collecting information about the identified needs. (M2);*

Secondly Inclusive Education Counsellors (IECs) also reported work overload:

*30 IECs cover more than 1200 schools in Palestine in 16 Directorates . They support schools to be able to include children with SEN, but their work load is huge. In addition, they try to address all areas of SEN (M1);*

And also for Ministers responsible for special educational needs:

*Working alone, without a team, has been very difficult. Too much to supervise: resources rooms, inclusive education, centres, training – overload becomes a barrier (M2).*

### **Lack of training and expertise**

Lack of training and expertise was seen as a barrier to development throughout the education system in Palestine. *‘Initial teacher training does not include SEN, and certainly not autism’ (M1) and IECs ‘lack a thorough professional training in SEN’ (M1). Interviewees pinpointed ‘lack of specialisation’ (M2) and the fact that ‘ teachers are not specialist’ (CP3) as barriers. The reason for this lack of specialist expertise was because ‘there are no universities in Palestine that offer courses in autism or any special needs courses’ (M1).*<sup>19</sup>

One interviewee felt there was a bigger problem with the preparedness of teachers for their professional role:

*The teachers come from educational institutions with no training at all, not only in dealing with children with SEN, but in education in general sometimes ... a big problem on top of everything is the pedagogy of education we have, it is very traditional [and] didactic. If I want to include a child on the autistic spectrum I need a lot of flexibility. I need a classroom that allows for different methodologies of teaching (T1).*

### **Lack of clear, shared, co-ordinated Government policies**

*‘I give a big part of the responsibility to our [Palestinian] Authority. Education is not the top priority. They have another agenda,’ (U1) said one person, adding ‘We have*

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<sup>19</sup> A Professional Diploma in SEN, the first in the West Bank, is now offered at Bethlehem Ahliya University.

*the Council for Special Education and People with Disabilities* [within the Ministry of Social Affairs.] *but they are not doing much*' (ibid). It was felt that there were '*no clear policies*' (M2) and in terms of disability rights '*We have laws but we are not using them*' (CP1).

There was thought to be no clear understanding of which government department should take responsibility for autism: '*The problem is that everyone wants disability to be under their umbrella, but it is all of us together to develop this sector. Everyone is responsible*' (U1).

Some felt it unhelpful that their successes were unrecognised: '*The challenges were seen but the successes were not easily seen*' (M2); or that, when they were, they went unrewarded by government support: '*We have a charity exhibition every year. We bring someone important to see our work, Minister of Education, Minister of Social Affairs. They are proud of our work but they do nothing*' (CP1).

Despite obstacles, resourceful resilience and refusal to be defeated ensures that there are opportunities to be found. Perhaps obstacles are the grit in the oyster and Palestinian people are their own best resource. In building on this human capital lie some of the answers to my main research question.

#### **Theme H: Opportunities and aspirations for future provision for children with autism**

This theme is at the heart of my research and the interview data indicated creative ways of thinking about the issues. People took the opportunity to acknowledge things that have been achieved in Palestine and were rightly proud of their successes: the '*hugely positive results (of the evaluation) for the resource rooms and the resource centres, the improvement in the children, the change in the behaviour and the*

*achievement of the children'* (M2), spoken of by the special needs team at the Ministry; the two disabled young adults helped towards an independent future by one of the centres in the community where *'we are very proud to see a person like this working and have a family'* (CP1); the building of *'beautiful networks for mothers of disabled children who are helping other mothers in their communities'* (T5), this from a senior teacher in Jerusalem; and the introduction by the Ministry of training in special needs for some inclusive education counsellors (M2). While none of these is specifically autism-related, these examples hold recognition of the importance of developing school provision, enabling brighter futures for young people with additional needs, fostering community networks and training professionals to work with special educational needs and set the climate in which developments are more possible within the world of autism.

The need for training is a key issue in the data. People stressed the need to do more to develop the abilities of teachers to work with children with autism. A key member of staff at the Ministry said that if *'a teacher needs to teach a child with autism or SEN she or he must be enabled to do this by providing opportunities for professional development through workshops or training courses'* (M1). He also suggested that the IECs, who support teachers could be trained to become specialists: *'They [the IECs] do not specialise in one particular area of disability, although this is a possible future goal within the team'* (M1). By building expertise, said one teacher, attitudes to conditions like autism would improve: *'Personally I believe it's working on attitudes. But how can you change attitudes? This can only take place if you give people the skills and the confidence and the training'* (T1).



One teacher saw the inclusion of children with differing needs as part of a wider move towards a philosophy and practice of education that would *'help students to think and develop imagination and relationships'*. He felt that education should *'develop children as human beings, as thinkers'* (T4).

One person pleaded for people who have commitment and passion in their role as educators saying *'We want people who have a heart here* [interviewee puts hand to chest], *to serve people'* (U1).

*'Changing the classroom environment'* (T1) was seen as important in meeting the needs of children with autism by one teacher, and a parent recognised that the changes that would benefit her son would also benefit other children, saying *'I wish we could have things that are adapted to his needs and this would help a lot of kids, not only Yousef'* (P2).

One interviewee felt it was important that responsibility for children with additional needs should not be handed over from teachers to teaching assistants, but that it should be a shared role:

*We need to change attitudes and we do this by giving the teachers extra skills, training teachers, having learning support assistants who work in partnership, otherwise we have another form of exclusion. It is too easy for the teacher to do it her own way if she has a learning support assistant who just works with that child* (T1).

There were differences of opinion: the success of the Resource Rooms project, celebrated by some, was not applauded by the teacher who saw Resource Rooms as working against inclusion rather than enabling it (p). Another difference of opinion related to mainstream versus special centres for children with autism, a debate that I found to ricochet through the literature I had consulted on inclusion, as discussed in

Chapter 3. Some people, rather than wanting inclusion within mainstream schools, wished for specialist centres for autism: *'I hope that in all Palestine they will have centres where they can help these children and their families, not only in Jerusalem or in Nazareth – any place in Palestine'* (PR2), said one practitioner, echoed by a parent whose child attended the Amira Basma Centre who said *'I hope the government will make like this service in every area in Palestine'* (P4).

I continue with this theme as it demonstrates widespread fertility of ideas and aspirations: hope not despair. Concern for the parents of children with autism was a common theme and several people spoke of the urgent need to support them:

*I wish the Ministry of Education and Ministry of Health in the West Bank would consider this as a big issue. There is a group of people [who] need a lot of help – even more than the prisoners<sup>20</sup>, because you can't imagine the suffering of parents. It is a human rights issue* (PR1).

*I hope we can help the mothers to help their children, how to work with them* (PR2).

*I want to support these parents* (CP1).

*They should teach the parents how to deal with their child* (CP3).

Potential benefits of working in collaboration with others to develop autism provision was an issue raised by some interviewees. One teacher said *'Collaboration? We've done that in academics with other schools. We can do that. Why not? The private schools do collaborate together'* (T3); another felt that the sharing of good ideas between teachers would be valuable: *'I believe if any model becomes successful then this can be helpful to reflect to other schools'* (T1). A community provider (CP1) at one of the centres felt they needed to be part of a wider international group sharing

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<sup>20</sup> Btselem, The Israeli Information Centre for Human Rights in Occupied Territories reports that 5369 Palestinians are held in Israeli prisons (September 2015)

an interest in autism education and he had sought membership of the Arab Network for Autism.

One interviewee felt that Universities in Palestine have an important role to play in the issue of provision for autism and that as well as providing specialist courses for educational professionals their work should be connected to research (U1) and should inform government strategy. Universities, he said, *'have the responsibility now to build policy'* (U1).

There was an abundance of ambition. One person said *'it is my dream that one day we should have a national centre where we say yes, we can protect autistic children, we work for their rights'* (U1). In Nablus there is indeed a new centre for children with developmental conditions such as autism: the An-Najah Child Institute, set up and run by An-Najah University in 2013 as a combined clinical, training and research unit, together with a kindergarten for children with autism is a pioneering first for Palestine. An overview of research data on developments in the education of children with autism in Palestine is given in Table 23. Undoubtedly there are others.

Some developments that have taken place in autism practice and provision	
1	Palestine held its first conference related to autism in April 2012, to coincide with World Autism Day, organised by the Special Education Centre at Ahliya University, Bethlehem. The conference was well attended and heard from a wide range of researchers, practitioners, parents and policy makers, resulting in an ambitious set of recommendations.
2	An-Najah University, Nablus, opened the An-Najah Child Institute (ACI) in September 2013. It will specialise in the field of child developmental conditions, including autism and is the first its kind to offer this specialism in Palestine. The Institute aims to offer a combination of diagnosis, management services for children, training of health and educational professionals as well as research initiatives. There is a kindergarten for 20 children with autism who will be catered for in 4 groups of 5.
3	The Ministry of Education has expressed the will and commitment to develop the field of education for children with autism (M1, M2, U1).

4	Resource rooms have been established in 36 schools to support children with additional needs. (There are disagreements about the way these are used (T1).
5	Following a recommendation [ (Karlsson, 2004) ] to provide post-graduate training in all aspects of SEN for the IECs, twenty of them are now being trained (M2).
6	Ahliya University, Bethlehem, has introduced a Diploma in SEN with a strong element of teaching about autism.
7	Princess Basma Centre has successfully opened a specialist centre of early years provision for children with autism, which could serve as a model for further developments of this kind. Funding is now secure, as they have now been licenced.
8	Friends School, Ramallah, is successfully including pupils with autism in a mainstream environment and are willing to share the expertise they have gained with other schools.
9	Outreach work in autism practice is taking place in the West Bank, led by trained professionals from Princess Basma Centre. This offers a model for how expertise can be shared.
10	An understanding of the philosophy and practice of inclusion has been established by the Terre des Hommes Inclusive Education Project in East Jerusalem. This offers a body of expertise to call on.
11	There are well-established centres of provision within the West Bank that are highly committed and ready to take opportunities to develop.
12	Parents' voices are becoming louder in their demand for better government services for their children with additional needs.
13	The Basha Behavioural Autism Tool (BAT) has been developed at Ahliya University and is a screening procedure for identifying children with autism. It has been developed to be culturally appropriate for Palestine.

Table 23. Some developments that have taken place in autism practice and provision

To round off this analysis of data set one, I return to the words of a member of the special needs team at the Ministry of Education: *'Autism is a "new area" in Palestine and is not widely understood by professionals or within society as a whole'* (M1). The data corroborates this opinion but has also shown growing interest in autism. Interest in my research has been shared by those I have spoken to in Palestine, one of whom said *'I think your contribution with your research is something great'* (U1). Many also voiced a wish to work together and be a part of developments in the field of autism provision.

I look next at findings from the Ministry of Education workshop (data set 2) before reflecting on the combined findings from both data sets 1 and 2.

## 6.2 Ministry of Education workshop (Data Set 2)

An opportunity for data collection arose when, at the request of the Special Needs department of the Ministry of Education, I gave a two-day workshop on autism practice in education for Inclusive Education Counsellors (IECs), Resource Centre professionals and Education Supervisors. 40 participants came from throughout the West Bank and East Jerusalem and included Ministry staff. As well as sharing my understanding of autism and education, as requested, I also wanted to ask this pivotal group of professionals for information and opinions about the education of children with autism in Palestine. Of the 36 IECs serving the West Bank and Jerusalem at that time, 31 (78%) of them attended the workshop. This was a remarkably large sample and offered an opportunity for comprehensive and reliable data.

My introductory hand-out (CD:E1) gave information about the research and allowed attendees to give their consent to participate. The programme (CD:E2) included four opportunities during the workshop to obtain data, as shown in Figure 31.

Ministry of Education Workshop – Four Data collection tasks	
i.	<b>Individual questionnaire</b>
ii.	<b>Focus Group 1:</b> <ul style="list-style-type: none"><li>a. Do you know of any children with autism in Palestine?</li><li>b. How are they educated?</li></ul>
iii.	<b>Focus Group 2:</b> <ul style="list-style-type: none"><li>a. Are there barriers to the inclusion of children with autism?</li><li>b. If so, what are they?</li></ul>
iv.	<b>Focus Group 3:</b> <ul style="list-style-type: none"><li>a. How could schools progress towards the inclusion of children with autism?</li><li>b. What are the existing strengths and weaknesses?</li><li>c. What changes are needed?</li></ul>

Figure 31: Data collection tasks – Ministry of Education Workshop

### **6.2.1 The Questionnaire**

A questionnaire (Appendix 9) was given, in Arabic, as an individual task at the beginning of the workshop. It was designed to gain an impression of what they knew about autism and educational issues related to autism, and to explore what they wished to know. The open questions allowed respondents to answer in a way that seemed appropriate to them. Responses would not necessarily reflect the totality of the respondents' knowledge but would give an indication of what was uppermost in their thinking. It would be a snapshot. Straightforward, simple questions helped to avoid difficulties with translation and might seem more attractive to participants at the beginning of a workshop and less like a test. Participants completed the questionnaires in Arabic individually in an allocated ten minutes. 36 questionnaires were returned, leaving four people who did not hand them in. The questionnaire gave three prompts:

- Prompt 1. Things I know about the autism spectrum
- Prompt 2. Things I know about supporting a child on the autism spectrum
- Prompt 3. Things I would like to know

Responses were translated, collated (Appendix 14) and analysed to find out what the participants' responses might reveal about their understanding, knowledge and perceptions of autism and inclusive education.

#### **Findings from Questionnaire Prompt 1: Things I know about autism**

For Prompt 1, each respondent's answer was broken down into distinct components, 139 components in total. An iterative process of scrutiny of the data for Prompt 1

suggested a thematic framework for analysis (CD:F2) as the responses fell into three broad themes (figure 32).

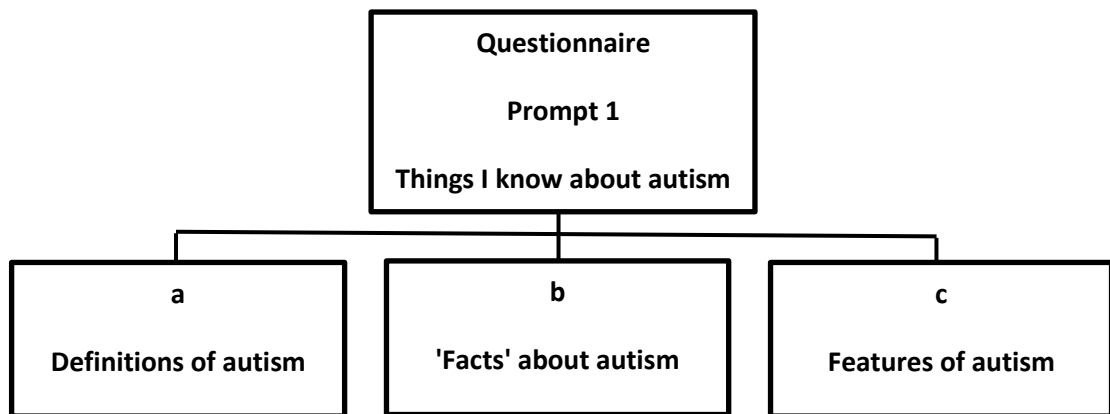


Figure 32: Thematic framework for the analysis of Prompt 1

### Definitions of autism

The first group of responses offered definitions of autism and I clustered these responses into six groups (CD:F3). The most frequently used term 'disorder' was used 14 times and it was interesting to note that the less negatively loaded terms 'condition' or 'difference' were not used by any respondents. Many respondents, 18 in all, offered definitions that used the vocabulary of 'disability', 'disorder' or 'dysfunction'. For example:

*Disorder of the nervous system which causes loneliness (R1) (R = Respondent)*

*A disease affects the child's nerves or the electrical waves in the body which cause a brain dysfunction (R16).*



*A kind of disability no one knows the real reason, maybe there are some genetic reason or maybe because of some kind of foods<sup>21</sup> (R 31).*

Eight definitions talked of 'illness and disease'. For example:

*Psychological illness affects the children (R20).*

*Maybe it is a mental disease, makes the child feel alone (R28).*

There were ten references to the brain or to the nervous system, such as:

*Disorder of the nervous system which causes loneliness (R1).*

*Also, it is a nervous disorder, the person moves a lot, make strange noises (R11).*

*It is a complicated disorder in the brain function (R33).*

*Mental disease affects their ability in doing activities and tasks (R27).*

Autism was defined by seven people in terms of psychological or emotional disorder.

For example:

*Emotional illness (R 5).*

*Psychological disease [that] affects the children (R6).*

The issue of behaviour featured in in only four definitions. For example:

*Social, behaviour disorder (R 22).*

*Behavioural disorder since the birth (R26).*

13 respondents referred to autism as something that affected children. This does not necessarily mean that they were unaware that it is a lifelong condition, and in the context of the workshop about children's education it was likely that minds would be focused on those of school-age, but raised the possibility of a misconception that autism only affects children. An example from this group is:

*The child can't communicate with others and lives in his own world (R 35).*

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<sup>21</sup> The language in some of these examples is taken directly from the translation of the data and may sometimes lack fluidity. I conjecture that this may be a feature of the translation and the respondent's original use of Arabic probably had greater fluency.

Table 24 indicates the number of responses that fell into each of these 6 groups

Definitions of autism - 6 groups	Code	Number of participants who gave responses in this group
Disability / disorder / dysfunction	1	18
Illness / disease	2	8
Involves the brain / nervous system	3	10
Psychological / emotional	4	7
Behavioural	5	4
Affects children (only children mentioned)	6	13

Table 24: How participants defined autism

### 'Facts' about autism

The second group of responses to Prompt 1 brought together other 'information' about autism. I have called this group 'Facts' about autism, and data fell into seven sub-groups. Data from this group is summarised in Table 25.

Five people made reference to the wide diversity within the autism spectrum, one of whom used the term 'spectrum'. For example:

*There are a lot of kinds, simple and complicated (R 5).*

*It is a huge spectrum (R 17).*

*There are 3 levels: simple, middle and complicated (R 22).*

Six people referred to the age at which autism appears and this varied from 'may appear at birth' (R6) to 'appears from the 1<sup>st</sup> to the 4<sup>th</sup> year' (R18). Four people (R6,18, 19, 22) mentioned that there appear to be more males than females. It was notable that only one person alluded to possible strengths in autism when (s)he said:

*Some autistic people are gifted (R21).*

There were other ‘facts’ that were given. Autism was described as 'developmental' by one respondent (R32); 'complex' by another (R33); and ‘affects the person’s life in all the fields’ by a third (R36). Three people made reference to the aetiology of autism: one person wrote that autism may be hereditary (R6) another that the causes were unknown (R5) and a third offered two ideas:

*Maybe there are some genetic reason or maybe because of some kind of foods* (R31).

One person made reference to the prevalence of autism but said that *‘its rate is 1/1000’* (R35).

<b>'Facts' about autism - 7 groups of responses</b>	<b>Code</b>	<b>Number of participants who gave responses in this group</b>
Wide spectrum / diversity	7	5
Age of onset	8	8
Males more than females	9	4
Can be gifted / strengths	10	1
Prevalence	11	1
Miscellaneous (only mentioned once)	12	4
Causes	13	3

Table 25: ‘Facts’ about autism given by the participants in response to Questionnaire Prompt 1

## Features of autism

The third category of responses to Prompt 1 described presenting features of autism. I clustered these responses into 8 groups and the frequency of each is shown in Figure 33.

'Communication difficulties' was by far the most frequently mentioned feature, given by 22 respondents (61%). Half of these (11 in all) gave answers that suggested that people with autism are unable to communicate, writing for example:

*The child can't communicate with others (R35).*

Nine people referred to behaviours which they associated with autism. Most used general terms such as 'certain activities and movements' (R21). Others were more specific including:

*Sometimes hits himself (R20).*

*Certain activities like shaking foot (24).*

*Person moves a lot and makes strange noises (R11).*

Twelve participants referred to solitariness in children with autism, expressing this in terms such as '*living in their own world*'(R14), '*loneliness*' (R1, 4, 8, 9), '*alone*' (R20, 21, 28) and '*introverted*' (R23).

Only one person referred to sensory differences in autism, writing: '*It affects the person's communication, skills, play and the senses*' (R18).

Three people (R1, 3, 8) said, in the words given here of one of them, a person with autism 'can't recognize what is happening around them' (R1), perhaps referring to difficulties with comprehending the social environment, although this was not clear.

Some individual ideas included one person's opinion that people with autism do not have feelings: '*he/she can't feel happiness, or sadness*' (R1). Another person said that children with autism have difficulty with '*academic skills*' (R32) and another said '*there is a difficulty in including them in schools*' (R34). Two responses cited difficulties with focus and attention (R23, 34).

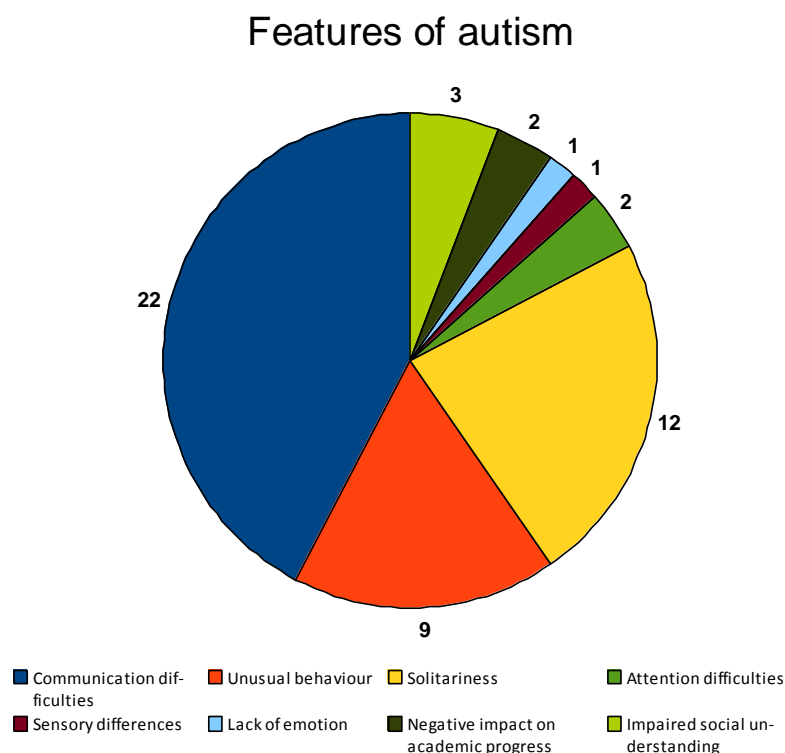


Figure 33: Features of autism given in response to Questionnaire Prompt 1

The emphasis on lack of ability, such as *‘can’t communicate’* or *‘can’t feel happiness, or sadness’* or *‘can’t recognize the things around’* suggested a view of autism that consisted of deficits. The responses did not indicate a shared understanding of autism and there were notable misconceptions: that people with autism are not able to feel happiness or sadness, for instance, and the more widely held misconception that people with autism are unable to communicate. The predominance of responses suggested a primarily medical model or deficit view of autism.

#### **Prompt 2: Things I know about supporting a child on the autism spectrum**

Respondents made fewer points in their answers to Prompt 2 than they had in Prompt 1 and data from responses to Prompt 2 were broken down into 55 components, (as opposed to 139 components for Prompt 1). As with Prompt 1, the

categories for analysis were derived from the data. The categories and distribution of responses were placed on a grid for further analysis (CD:F4) and findings were then summarised (CD:F5).

Responses in this group included medical words such as '*treatment*', '*medical*', '*rehabilitation*', '*medicine*', '*speech therapy*', '*occupational therapy*' and '*specialist*', (unless it was made clear that they meant an education specialist). Responses in this group are shown in Table 26.

<b>Responses to Prompt 2 (Things I know about supporting a child on the autism spectrum ) using 'medical' terminology</b>	<b>Respondent</b>
Treat and rehabilitate them.	1
The autistic children need special rehabilitation programs.	15
Give treatment by some medicine.	16
They need psychological, social and academic rehabilitation from specialists	20
Offer help like speech therapy, occupational therapy.	23
Make a treatment plan for each student with many specialists like: speech therapy, educational therapy... etc.	5
Needs different specialist to help.	26
Offer a special rehabilitation programme.	29
Depend on the medical report to diagnose.	34
The autistic people need special programme rehabilitation.	35

Table 26: Responses to Prompt 2 using 'medical' terminology

The largest group of responses (11 in all) to Prompt 2 referred to the need for specialists. Of these, six are also included in the 'Medical approach' group (above) as they refer to medical specialists. The remaining five responses (Table 27) however came from respondents who perhaps saw a need for specialists who were not necessarily medical.

Responses to Question 2 - Need for specialists	Respondent
He needs special programs.	4
These children need special education and to use special techniques.	14
Offer special education programs.	27
Establish some foundation to help them.	28
We must collaborate with the associations that are working with the autistic children.	31

Table 27: Responses to Prompt 2 - Need for specialists

Two respondents referred to lack of capacity for supporting children with autism. One was a personal reflection:

*I can't give help to autistic children, and I would like to know how. Also, I am working hard to accept the autistic children in our society, and to support them (R7).*

The other was a comment on Palestinian schools:

*There is no support for them especially in the governmental schools (R9).*

Five respondents referred to the issue of inclusion. Inclusive education is a key policy within the Ministry of Education and indeed all participants held roles directly related

to the implementation of this policy. Of the five responses relating to inclusion, four (R7, 11, 12, 23) could be seen as positive. For instance, one person wrote:

*I am working now with governmental schools to support autistic children (R12).*

Another respondent said:

*Include these cases into schools (R23).*

A fifth respondent acknowledged the challenge of including children with autism:

*To include a child with autism in a normal class is a hard thing except for the simple kind (R5).*

Sixteen respondents mentioned non-medical approaches and interventions and this data is summarised in Table 28. Of these sixteen, six made two points each, two made three points each and the remaining eight made one point each. There was no uniformity within the responses and most of the responses were singular and individual.

Three respondents made reference to named interventions commonly used to support children with autism. Two named TEACCH (R18, 19), all three named PECS (R18, 19, 32) and one of the three also referred to 'behaviour modification' (R32).

Some responses were not autism-specific. For example:

*Offer the child a comfortable place (R17).*

*Take the children on tours and picnics (R13).*

*Praise them (R17).*

The need to get to know and understand the individual child with autism was referred to by one respondent.

*We must know their needs and how to have their trust (R30).*



Two people referred to communication in their responses. One said that we should teach children with autism how to communicate with others (R8), whereas the other suggested that we should learn how to communicate with them (R24).

Two people showed an awareness that children with autism may not cope well with change. One suggested:

*Organise the place and do not change it, because the child likes routine (R21).*

As well as the three respondents who mentioned PECS (referred to above), another also made reference to the use of pictorial approaches:

Teach them by pictures and drawing (R17).

Approaches and interventions given in response to Prompt 2		Number of participants who gave this response
G	Early intervention	2
H	Support family	1
I	Individualise approaches	3
J	Praise	1
K	Use music in teaching	1
L	Develop independence	1
M	Trips and picnics	1
N	Good education	2
O	Communication	2
P	Avoid changes	2
Q	Teach them by pictures / drawings	1
R	Offer a comfortable place	1
S	Build trust	1
T	Teach life skills	1
U	Named interventions	3

Table 28: Responses to Prompt 2 - Approaches and interventions

The comparative sparsity of responses to Prompt 2, in contrast to Prompt 1, may suggest low confidence in knowing how to support children with autism in education. Data did not suggest that the respondents were confident and knowledgeable in how to support children with autism in education. However, despite some recognition that inclusion for children could be challenging, there was no suggestion that they should be excluded. Indeed several responses suggested a positive willingness to include children with autism. As with Prompt 1, many responses used language that suggested a medical bias in thinking about autism and the numerous references to the need for specialists seemed to imply that the education of children with autism might not be considered to be within the professional range of schools. There was a wide range of individualised responses that proposed approaches that could be used with children with autism. A few of these were clearly autism specific (eg. TEACCH and PECS). One participant mentioned the need '*organise the place and do not change it, because the child likes routine*', a key aspect of providing an autism-friendly environment. In general, however, responses, although arguably useful, were not autism-specific. As a whole, responses suggest that while there are pockets of awareness of good practice in relation to children with autism, there appears to be no consistency or coherence of understanding across this group of key education professionals. 26% of the responses, as shown in Table 26, indicated a medical model of supporting a child on the autism spectrum.

### **Prompt 3**

#### **Things I would like to know**

Prompt three was included to enable me to take participants' wishes into account during the workshop. As it turned out it was not possible for them to be translated in

time for me to do this. However the responses are a useful indicator of priorities for this group. Hopefully most of the issues raised were adequately dealt with in the workshop and participants found the workshop useful, although there is one area where this may not have been so: the high level of interest in diagnosis of autism (further discussed below) suggests that participants would have liked more coverage of this topic.

Responses to Prompt three were analysed using nine categories drawn from the data (CD:F6) and summarised (CD:F7). One participant did not respond to this Prompt. The other participants made between one and four points in their responses. The highest number of responses related to how to work with children with autism, variously expressed as how to '*work with*', '*deal with*', '*teach*', '*help*' and '*support*' these children. One person also wanted to know '*how to support their teachers*'. Altogether there were 32 questions about how to support children with autism. Three of these were specifically about inclusion:

*How to include them in schools (R25).*

*If there is a possibility to include the children in the schools (R22).*

*How to include them (R5).*

5 people had more specific requests for information about the following:

*What are the centres that can help them (R20).*

*How to decrease their movements when these movements can hurt them (R23).*

*Early intervention (R25).*

*If there is a treatment whether by medicine or special programmes (R32).*

*How to treat them psychologically and medical (R36).*

Six people wanted to know the causes of autism. Eight gave responses that were grouped together as 'What is autism'. Of these eight, four wanted to know the 'symptoms' or 'characteristics' of autism, three wanted to know about the different types of autism and one asked for a '*model definition of autism*'.

Diagnosis of autism was a key issue and 44% of participants said this was something they wished to know about. One person also wanted to know 'how to evaluate their skills and abilities' (R9).

The largest number responses, given by 80.5% of the participants, was about how to work with and support children on the autism spectrum.

### **Overview of findings from the questionnaire**

Taken as a whole, responses to the questionnaire indicated that a medical model of autism was foremost and autism was conceptualised in terms of deficits. There were notable misconceptions, including the notion that children with autism cannot feel emotions and cannot communicate. Responses also suggested a lack of knowledge about autism-specific approaches in education and an absence of shared understanding about how to support children with autism in schools although there was strong indication of a willingness to develop knowledge and skills and a wish to promote inclusion for autistic children. These are key findings, given that the respondents represented a sizeable proportion of the professionals who are best placed to be able to influence the inclusion of children with autism in Palestine.

### 6.2.2 Focus Group discussions at the Ministry of Education workshop

Three focus group discussions were interspersed throughout the two days of the workshop (CD:E3). Group size and time allocation for the focus groups was predetermined (Table 29).

Focus group discussions – Ministry of Education workshop				
	Number of groups	Group size	Time allocated	
			for discussion	for feedback
Discussion 1	5	8	5	6
Discussion 2	5	8	20	8
Discussion 3	4	10	20	8

Table 29: Focus group discussions – size and duration

Participants gave verbal and flipchart feedback from their discussions. The verbal feedback from the groups was translated *in situ* and recorded by digital voice recorder. I later transcribed the recordings (Appendix 15). Flipcharts were photographed (CD:G5) which proved useful as the recording of the third discussion was inaudible. So for discussion three the flipchart was translated (CD:G4) to provide data. For the first Focus Group, two closed fact-seeking questions (Table 31) were given to the groups. Responses were collated to provide data as discussed below. For Focus Groups 2 and 3, participants were invited to respond to more open questions (Figures 30 and 31 below). Focus Groups 2 and 3 were analysed thematically. Findings from the three Focus Groups are now presented separately, each followed by a short overview. After this the findings from the contextual enquiry as a whole (data sets one and two) are brought together and commented on.

## Focus Group 1

### Focus Group 1:

**Do you know of any children with a diagnosis of autism?**

**How are they educated?**

Table 30: Questions for Group Discussion 1

From the translated transcriptions of the feedback to Focus Group 1 (Appendix 15) points of information were summarised (CD:G2) offering the following findings.

Eight children with autism were identified by the participants (two girls and six boys):

- Two children are currently included in mainstream.
- Two children have been included in mainstream schools for a period of time but are no longer at those schools.
- Two more children attend special centres.
- Two children have no educational provision.

The following points were made about provision for autism:

- The Friends of Autistic Children Society offers a range of approaches in meeting the needs of children with autism. These include visual supports to develop language acquisition and TEACCH approaches and there is some use of behaviour modification programmes, designed by a psychologist who specialises in this field. The society also offers speech therapy. The children may not have clear diagnoses and they begin by making an assessment of the child.
- Resource Centre staff have a significant role to play in trying to place children with autism.
- Schools cannot be forced to take children.
- There is professional frustration about the difficulty of making appropriate provision for these children.
- Children are often prescribed medication.
- Parents sometimes take their children abroad for advice and treatment. One child was taken to China for stem-cell treatment.
- Parents are desperate and sometimes search the Internet for advice.
- Doctors and psychologists are not qualified to diagnose autism and do not have a good understanding of it.
- There is a lack of information.
- Special centres in Bethlehem are working with autistic children.

## Overview of Focus Group 1

Data gave a useful snapshot of the situation in schools and suggested that very few children with autism are currently knowingly catered for in schools in Palestine. I estimate that the 31 IECs who participated in the workshop equated to 78% of the total number (36) in the West Bank and East Jerusalem. It is not unreasonable to surmise that, between them, they support a proportionate number of schools (78%), in which case the identification of a mere eight children with autism is startling. In the UK that would look more like the number for one school.

## Focus Group 2

<b>Focus Group 2</b>
<b>Are there any barriers to the inclusion of children with autism in schools in Palestine?</b>
<b>If so, what are they?</b>

Table 31: Questions for Focus Group 2

Feedback from animated discussions (Appendix 15) were analysed and mapped to identify themes (CD:G3). The following barriers were identified:

At a personal and professional level:

- Lack of expertise and training for educators at all levels.
- Low professional morale.

At a political and institutional level:

- Inadequate or unclear policies.
- Unwillingness to take responsibility for these children. The Ministry of Health says it is not a disease therefore not their responsibility. The Ministry of Social Affairs says it is too costly to make provision. Ministries need to work together. Training is needed for the other professionals as well as educators.
- The Bureau of Statistics does not include autism as a category in its census.

So autism is 'hidden'.

- Lack of specialists and good specialist centres. Scholarships to study abroad are given to others but have not to anyone wishing to specialise in autism.
- No reliable diagnosis of autism in Palestine. A team approach is needed for diagnosis and there are no teams.

At a schools level:

- Negative attitudes within administration, teachers and students.
- Inadequate physical environment in schools is unsuitable for autistic children.
- Low teacher pay and status.
- Schools cannot cope with aggressive, self-injuring or unsafe behaviour.
- Early intervention is lacking to prepare children for admission to school.

Family and Society level:

- Lack of financial stability.
- Negative attitudes in society leading to rejection of these children.
- The media do not highlight this issue but have the potential to change attitudes towards autism.
- Parents do not assert a demand for better provision for their children.

## Overview of Focus Group 2

Findings suggest that lack of skills, knowledge and understanding at all levels, governmental, societal and within schools and institutions, constitute a barrier to the inclusion of autistic children. This is matched by lack of collaboration across government departments towards addressing the needs of children with autism.

## Focus Group 3

<b>Focus Group 3</b>
<b>How could schools progress towards the inclusion of children with autism? What changes are needed? What are the existing strengths and weaknesses?</b>
<b>What recommendations would you make?</b>

Table 32: Questions for Focus Group 3



Coming towards the end of the two-day workshop, Focus Group 3 stimulated dynamic discussion about the way forward. As explained above, the flipcharts provided the data in this instance. Data were analysed to identify perceived strengths, weaknesses and recommendations in relation to the inclusion of children with autism in Palestine. Responses from the four groups overlapped and were mapped thematically (CD:G7). They are summarised here.

**Existing strengths:**

- An Education For All policy that states the right for everyone to learn.
- MoEHE has a policy for inclusion.
- Schools have programs for special education.
- The administration team inside the Ministry cares about special needs students.
- Resource rooms, inclusion classes and training workshops.

**Existing weaknesses:**

- No specialist teachers for autism.
- Lack of specialised centres.
- Lack of finance.
- No statistics.
- No qualified staff and no support policy.
- Environment and staff are not welcoming towards these students.
- Academic assessment of pupils is not adapted for those with special needs.
- No long-term strategies.
- The policy is out of date and does not address the needs of autistic children.
- Lack of diagnosis.
- Negative attitudes.
- Lack of adequate media coverage.

**Participants' recommendations:**

The wealth of suggestions is condensed as follows:

- Develop a clear policy to give more attention and resources to this issue. This will lead to better educational provision for children with autism.
- Create specialists and provide training for all.
- Raise awareness of this issue at social and professional levels to change attitudes.
- Share knowledge and experiences with people in other countries.

- Develop a program for early diagnosis.
- Ensure better coordination between the Ministry and associations working in this field.

### **Commentary on Focus Group 3**

Despite lack of knowledge, skills and strategic planning; and despite negative social attitudes, shortage of finance and an unclear picture of the extent of the problem, there exists commitment towards inclusion for children with autism. There was interest in autism, aspiration to include children with autism, and useful suggestions for action. Suggestions included the need for co-ordinated policy development, getting to grips with the issue of diagnosis and identification, training and widespread sharing of knowledge, collaboration between interested parties in Palestine and also across national boundaries.

### **6.3 Synthesis of findings and commentary on the Contextual Enquiry**

I preface this section with a reflection from my field notes (Table 33) in relation to the image below (Figure 34)



Figure 34: Against the Wall (Banksy, 2005): The Art of Resistance in Palestine

**Extract from field notes 11/12**

The separation wall in Palestine must be the longest gallery of resistance art and free speech in the world, with tens of hundreds of examples along its length. The Bristolian artist, Banksy, captured some of the spirit of Palestinian resistance with this mural of the little girl soaring precariously aloft to a place above the confines of her prison wall. This aspiration to rise to a better place comes alive in my data. Early on in my research I asked myself whether Palestinians, with so many daily struggles to deal with, would have the time or interest to think about the needs of children with autism. The impression that I have formed is that the frustrations of the occupation have sharpened the interest of Palestinians in education and social justice and that now is the time that those aspirations for something better are ready to be extended towards children with autism.

Table 33: Extract from field notes 11/12

In this section I return to some key research questions as a framework for drawing together and discussing findings from data sets one and two.

### **6.3.1 How is autism understood in Palestine**

‘Palestinian society doesn’t understand autism’ (Parent, FN 7.11.12).

I should first be clear about my own understanding of autism as this gave me the lens through which I interpreted what I encountered. I understand autism to be a lifelong, neurological condition that affects the way in which a person communicates and relates to people and the world around them; autism is a spectrum and there is a wide diversity of ability within that spectrum, so that no two people with autism are the same; autism is a transactional condition and children with autism can be helped to develop and progress through our understanding of their needs and the provision of a suitable environment and an appropriate education. My understanding of autism gives me a positive attitude towards people with autism and a recognition of their rights to inclusion in education and in society. My research findings point towards a spectrum of understandings of autism in Palestine ranging the gamut from one

parent's appraisal of her autistic child: '*He is amazing, he is a gift*' (P 3), to sad stories of parents who hide their child away (CP1) or the education official who, reportedly, referred to children with additional needs as '*the idiots*' upon whom resources should not be wasted (M2). The data provided examples of unfavourable attitudes towards autism and special needs (Table 14, p135) in contrast to which the positive comments like '*He is amazing*' shine through as exceptions. The data suggest a symbiosis between knowledge and attitude. For example, the above parent (P3) who spoke so positively about her autistic son told of the early days of her journey when, she said, '*I was crying all the time because all my dreams they were smashed*'. She had trawled the internet, read many books, especially about the experiences of other parents, and got her brother in the States to send books and resources. Knowledge had led her to a change of attitude. Attitudes in Palestine are changing (Table 15, p.136) and one of the reasons for this is perhaps greater knowledge and awareness gained through the media (T1).

The way in which autism is conceptualised and talked about, in the UK at least, has taken account of new insights into the nature of autism and a greater acceptance of autism as a difference rather than a deficiency (Stanton, 2013). Often it is preferred to talk of autism as a 'condition' rather than a 'disorder' (Jones et al., 2008) and there is a growing tendency to focus on the strengths and abilities associated with autism rather than only thinking about the difficulties (Mottron, 2011). The disability rights lobby in the UK and the West has also helped us to think carefully and revise the words we use. An analysis of the language used in the answers to the questionnaire shows that the words chosen were predominantly oriented towards deficits rather

than strengths when describing autism, words such as *'disorder'*, *'dysfunction'*, *'disease'* and *'illness'*, as I have indicated in Table 21. The negative view of autism, held here in the language, correlates to the experiences of Ahmad's parents (Table 10, p.192) who foresaw social hostility towards their son; it also matches the wealth of evidence from the interviews of social stigma and social exclusion (Table 14, p135), and corresponds to the findings of Dababnah & Parish (2013). As with the parent in the previous paragraph whose attitudes towards her son changed as she gained understanding, it is possible to conjecture that negative attitudes stem from lack of knowledge. The interviews revealed widespread lack of knowledge about autism (Table 13, p130), summed up in the words of a member of the special needs team at the Ministry: *'People who know about autism are rare in Palestine'* (M1). Lack of awareness of the breadth of the autism spectrum is highlighted in both sets of data: several interviewees (data set 1) said that autism is equated with low intelligence and that it is not understood that children with autism can also be of average or above average intelligence; this was borne out in the workshop data (data set 2) where there was only one mention of ability as opposed to disability and a deficit and medical model of autism predominated.

Data set one indicated recourse to medication such as Ritalin and biomedical approaches such as stem-cell treatment. The Defeat Autism Now (DAN) network, to which one centre referred parents, uses discredited bio-medical approaches (Fitzpatrick, 2009) such as hyperbaric oxygen treatment and chelation, unproven at best, dangerous at worst (in the case of chelation). The National Institute for Health and Care Excellence (NICE, 2013) states unequivocally that these treatments should not be used to manage autism in children and young people. Parents spoke of their

scouring of the internet to find answers in the absence of anyone to turn to and it is of concern that parents in need of support are vulnerable to misinformation and charlatanism. This is true of parents anywhere, but perhaps more so in a region such as Palestine where there is a lack of support for parents.

Both data sets attest to strong interest amongst participants in developing understanding and expertise in relation to autism. This was prominent amongst the workshop participants (data set 2) where 80.5% participants wanted to learn more about autism in order to be able to support inclusion. Their suggestions included the need for training, a need that also emerged strongly from the interviews and visits discussed in data set 1 (p.163). Training is a key issue within the recommendations from this research.

### **6.3.2 How are children with autism identified, educated and supported?**

Data showed that diagnosis is problematic in Palestine and that few children with autism are identified. Absence of government statistics on the incidence of autism emerged as an issue in both data sets and in the words of one person, autism is 'hidden' in Palestine. The lack of identification of these children was a key issue causing difficulties across the board: for teachers, for parents, for policy makers adrift in uncharted waters and for medical professionals lacking expertise to reliably diagnose autism. Queries as to whether the incidence of autism was the same in Palestine as in Europe arose in the Ministry workshop and in the absence of diagnosis and statistics it is impossible to be sure but the literature proposes that autism is a universal phenomenon (Daley, 2002; Feinstein, 2010) and the research

evidence does not give credence to a notion of geographical differences in the prevalence of autism (Daley, 2002; Ben-Sasson, 2012), or indeed to differences related to ethnic or sociocultural factors (Elsabbagh, 2012). On that basis, it is tempting to extrapolate that there are many more children with autism than are identified. Based on figures for 2010, there were about 1,250,000 children in the West Bank and East Jerusalem (PASSIA, 2011); an autism incidence rate of 1%, the incidence rate estimated for the UK (Baird et al., 2006), would predict the likelihood of 12,500 children with autism across the region. In West Bank and Gaza as a whole that number could rise to 20,000. This incidence rate rises to 1 in 68 in the USA (Centre for Disease Control and Prevention, 2014) and that would predict an even higher number. There are various things to consider here: possibly there are children in school who are not diagnosed; possibly there are children who are not in school but are catered for in centres, not under the jurisdiction of the Ministry; possibly there are children with autism who remain at home. The surprising finding in the workshop that only eight children with autism were identified (p.184) holds the possibility that participants knew of other autistic children but did not mention them and I cannot be sure that this was not the case. However, when this data is looked at in the context of other findings, a picture emerges of a large number of children whose educational needs are not met. This was a source of frustration to participants, whose comments indicated that these children's needs are neglected.

A factor affecting diagnosis, previously mentioned, is that autism may look different in different countries (Matson, 2011), and cultural norms affect perceptions of it and maybe also cultural milieu affects the development of autism. These are interesting issues beyond the scope of my research but it is an area that is usefully being

explored (Koh & Milne, 2012) and indeed, in Palestine, Dr Basha has made cultural consideration in the compilations of the Basha Behavioural Autism Spectrum Disorders Screening Test (BAT) as discussed above (p.132). A better understanding of the autism spectrum has led, worldwide, to an increase in the identification of autism (Grinker, 2009) and it can be expected that a better understanding of autism in Palestine will be accompanied by a 'growth' in autism.

The lack of reliable diagnosis of autism in Palestine is a significant issue for education. Although provision should be needs-led rather than diagnosis-led (DfES, 2002; NIASA, 2003) and diagnosis does not tell you what you need to do to educate the child it would be simplistic to deduce that it is therefore educationally unimportant. The risk of not identifying children through accurate diagnosis is that without it autistic children will be misunderstood and given different labels such as 'naughty', 'stupid', 'badly brought up', 'ineducable', 'mentally retarded' and so on. The issue of diagnosis, practice and provision are closely entwined. There is a need to diagnose and identify autism, and to do so at an early age, but this need goes hand in hand with a need to understand it and put in place approaches and school environments that enable children with autism to be included in education. Schools need to understand autism and be able to make appropriate provision for it. The literature shows that education in Palestine is traditional, teacher-centred and didactic (Khaldi & Wahbeh, 2002; Farrell, 2007; Al-Ramahi & Davies, 2002; Karlsson, 2004). We have also seen that schools can be poorly resourced and accommodated (Reimers, 2012; UNICEF, 2011; Wahbeh, 2011). But the other side of the coin is that there would need to be a better understanding of practice and provision.



The education of children with autism is challenging; autistic children do not respond, behave or relate to others in the same way as neuro-typical children and the school environment can be hugely challenging for them. This, coupled with the low rate of diagnosis and the limited understanding of autism make it unsurprising to find evidence that Palestinian teachers, professional and policy makers have found it difficult to address the needs of children with autism. Findings from data set one affirm the view that key professionals lack the knowledge and understanding to enable them to have confidence in supporting children with autism. I found a lack of appropriate provision and this correlates to the literature relating to autism in Palestine (Zayed and Banifadel, 2012; Dababnah and Parish, 2013).

Data set one gave voices calling for the very things that stack up in the literature as the building blocks of good autism practice: the need for knowledge and understanding (Jordan & Powell, 1995); the need for teachers and practitioners to be supported and to work together (Charman et al., 2011, Parsons et al., 2009); the need to promote empowerment and confidence of teachers (Cumine et al., 2010); the need for education that develops the whole child rather than just drilling them to acquire a set of skills (Prizant & Wetherby, 2006); the importance of environment, a particularly apt one for autism (Jones et al., 2008); and a recognition that what would be good for an autistic child might well be good for other children (Jordan, 2005).

Heart-warming evidence (data set one) of dedicated people in the communities making compassionate provision for children, included some with autism; in addition to those I visited there are others that I heard of, and doubtless others that I have not heard of. There were beacons of good practice that stand as exemplars for others. Many centres, with the notable exception of the Friends of Autistic Children Society,

were set up to cater for children with a range of challenges. However, in the recent few years three of these centres ( Amira Basma Centre, Star Mountain Centre and Tulkarem Rehabilitation Centre) had set up discrete groups to work with children with autism, recognising that their needs were different; and this recognition was clearly present in a fourth centre (Annahda Women's Centre) as they deliberated on what to do about it. The dependency of these centres on charitable funding is challenging and precarious and community providers would have welcomed government funding to secure and give recognition to their work. Their work was admirable but resourcing was frugal. Both data sets suggested that of the autistic children who were catered for, it was more likely that they would be those with the fewest challenges, the 'good children' (Table 10, p.123) and those whose autism was of 'the simple kind' (p.179).

As for the schools, the data did not indicate a discrepancy between the official government view and that of professionals and people in the community in relation to the inclusion, or otherwise, of children with autism. Interviews with Ministry staff and the workshop with Ministry staff did not give a favourable gloss to the situation. On the contrary, there was strong evidence that the special needs team at the Ministry and the IECs were aware and ready to acknowledge that they had not yet been able to address the needs of children with autism. The clarity of this corresponded closely to the perceptions of those not close to government. Where perhaps there was a conflict of opinion was in the perceptions of community providers that there should be government funding for their work. In the words of one of the community providers:

'They are proud of our work but they do nothing'<sup>22</sup> (CP1).

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<sup>22</sup> The salaries of some of the teachers at this centre are in fact paid by the MoEHE and this is also the case at some other centres, but not all. My research has not established an overall picture of this.

To return to the issue of inclusion of children with autism in schools, although the evidence from both data sets suggests that there are very few children in schools who are identified as having autism, there may well be, as one participant commented (T1), children with autism who have not been identified. In the UK, 70% of children with autism are educated in mainstream schools (Charman et al., 2011), a figure that astounded people to whom I mentioned this, but I do not hold this up as a holy grail for Palestine. There is a clear interest in the Ministry of Education to develop provision for autism and the status of the centres and how they fit in to Palestine's vision of inclusion and 'education for all' is an issue to consider and one that I return to in the final analysis in Chapter 9 where recommendations about developing practice and provision for autism must take into account the fact that Palestine has, at present at least, limited resources and so there needs to be an emphasis on ways forward that are cost effective and within the realm of what is fiscally possible.

### **6.3.3 How is inclusive education regarded in Palestine?**

The literature pointed to a positive attitude and progress towards educational inclusion in Palestine (Opdal et al., 2001; Gumpel, 2003; Ministry of Education and Higher Education, 2008; NAD, 2010; Farrell, 2007) and this positive acceptance of inclusion was borne out in the findings from data sets one and two. I concur, however, with Farrell's study (Farrell, 2007), which points to a lack of shared understanding of what inclusion means. For some in my study, inclusion was a locational issue and it was about training support staff, not teachers; for others it was about flexible approaches to teaching; for others it was about providing resource

rooms in schools. Chapter 3 gave a view of educational inclusion that is about enabling participation by thinking about the environment into which we are trying to include all children. The nub of this is a distinction between inclusion and integration. The lack of shared clarity of what inclusion is profoundly relates to educational practices. There is a need to think about what inclusion means for autism and to consider whether inclusive education necessarily means the same for Palestine as it does in the UK or elsewhere. My final chapter explores this further, together with Farrell's (2007) advice that 'at no time should the diagnosed problems of an individual or group of children be seen as a reason for excluding them from mainstream schools' (p.4). I also build on the idea that inclusion is also about the way professionals and communities work together, as discussed in Chapter 3.

#### **6.3.4 What is the experience of families and what is their relationship to other stakeholders?**

Some interviewees spoke of their work to empower parents to encourage them to demand better government services and to support each other (CP1, T5) and, one teacher said that parents were now more vocal in their demands: *'Parents' voices are being more and more heard and they are really seeking help'* (T1). A community provider observed the lack of resources for young people above school age and wanted to *'open a class for others who are above 18 years old and who have the ability to work in the sheltered workshop'* (CP1). This concern for the long term well-being of those with autism is also one that is flagged up in the literature (Wittemeyer et al., 2011).

My reading (Parsons et al., 2009; Charman et al., 2011; Jones et al., 2008) persuaded me of the need for interested parties, or stakeholders, to share knowledge and work together, bringing together professionals from education, health, members of the community and, importantly, parents, families and people with autism. Data from the workshop (data set 2) did not show this to be a prevalent notion within this group of education professionals, although Focus Group 3 did reveal a desire for better collaboration between the MoEHE and associations working in the field of autism, as well as between the various government ministries. However, there was little mention of parents and families. Parents were referred to in Focus Group 2 where it was felt that 'parents do not demand for better provision for their children', a view that perhaps sees parents as lone warriors rather than partners. Partnership with parents was not a notion suggested by the data from the workshop. However, data set one differed for although there was much evidence of parents isolated at home and without support, most of the centres in the community that supported children with conditions such as autism and their families showed awareness of the importance of working with parents and this was one of their strong features.

Literature in the UK emphasises the importance of the child's voice when making decisions about his or her education (Parsons et al., 2009; Hesmondhalgh, 2006) and indeed, in our understanding of education for children with autism, the autistic voice has been of paramount importance, enabling us to comprehend the different perspectives of children with autism and adapt our approaches (Grandin, 1995; Williams, 1999; Sainsbury, 2000; Milton, 2013). There was no data to support the idea of collaboration with people with autism, either by listening to the voices of children with autism or by listening to autistic voices within the community.

### **6.3.5 What are the barriers to inclusive education for children with autism in Palestine?**

The same concerns emerged from both data sets. However, although the unstable political situation and the occupation featured pervasively as an underlying factor in the interviews and the visits of data set one, this was not so in the ministry workshop (data set two). The reasons for this are unclear but perhaps the professionals who participated in the workshop felt it more productive use of their time to focus on the things that could more easily be changed. Perhaps the barriers that keep children with autism out of schools are easier to tackle than the obstructions that exclude and imprison the society as a whole.

Both sets of data show a key barrier to be the lack of expertise and knowledge with little or no access to training for professionals or advice for parents. This is perhaps the fundamental barrier, as knowledge and expertise is needed to guide policy, improve practice, change attitudes, allow for better identification of autism and enable more effective parenting. Training and knowledge sharing is therefore a key issue for my final analysis in Chapter 9. It is not straightforward, however, as a look at other barriers will show. Lack of finance was mentioned often, so that the way forward is bound to have to involve careful allocation of precious resources and a concentration on affordable solutions. The prevalence of traditional approaches to teaching are an important aspect of what needs to be addressed, as is the need for a shared understanding of autism, and of what inclusion means for Palestine.

There is conflicting data for the question of responsibility and whereas data from the MoEHE workshop suggests that no department wants responsibility for these

children, previous interview data suggested everyone wanted them to be 'under their umbrella' (U1, p.162).

## **CHAPTER 7: FINDINGS FROM THE CASE STUDY (Data set 3)**

I have looked at the contextual enquiry strand, the macrocosm, drawing on data from data sets one and two, and I now move on to strand two and data set three. This is the case study, the microcosm. Research questions are the same but the perspective is different and will hopefully 'illuminate the general by looking at the particular' (Denscombe, 2010:53). Here there are two 'particulars' as I undertook a 'paired' case study involving two different educational establishments: Friends School in Ramallah and Amira Basma Centre in Jerusalem. I explained in Chapter 5 how the choice of the two settings did not meet my original criteria, as neither school was a government school. Despite this, the special needs team at the Ministry of Education showed interest in my research and I am indebted to them for their lasting support. Although my criterion of at least one government school was not met, the second setting, Amira Basma Centre in East Jerusalem, was by no means a disappointing alternative as it contributed enormously to the richness of my data. They differ in terms of location, the social background of their students, their historical beginnings, curriculum and affiliations. Whereas the Friends School was involved from the outset, Amira Basma Centre only became involved eighteen months later, in November 2012, so their involvement was much less. They have in common a desire to address the needs of their students with autism and to include them alongside other children. Interestingly for my research, although very different they each have diverse areas of developing expertise from which the other can learn. My Case Study is primarily qualitative and I worked with groups of staff in these two settings to develop practice and gain insights into the meaning that this held for the participants. This chapter draws on a rich variety of data (Table 4, p.87). I discuss my findings within a



descriptive analysis, saying what happened and how I interpret what happened as the research evolved with each of the two settings in turn, before looking at both together. First I introduce the two settings.

### **7.1 Introduction to the two settings**

Friends School in Ramallah is a private school, founded by American Quakers as a school for girls in 1869. A boys' school was added soon after and in recent times both schools have become co-educational. The Friends Girls' School (FGS), still so called, is now the elementary school with a kindergarten, and pupils of secondary age attend the Friends Boys' School (FBS). It is the lower school (FGS) that participated in my research. I refer to it as both FGS and Friends School. Set in the old city of Ramallah, in gracious stone buildings surrounded by trees and plants, FGS provides a calm and attractive environment for the 650 or so children who go there. The school aspires to have students from diverse social, religious and economic backgrounds although the fees would be beyond the reach of many Palestinian families. To the eyes of a visitor from a more economically advantaged region of the world, however, the facilities and resources in the school would seem modest.



Figure 35: Friends School, Ramallah Old City

The school ethos is strongly based on its Quaker values, setting it apart from other schools in Palestine. These values include integrity, honesty, cooperation, compassion and acceptance of diversity. Each class has a weekly lesson entitled 'Problem-solving and Ethics' where positive relationships between pupils are encouraged and conflict resolution strategies are taught and practiced. The transfer of these skills into the daily life of the school is fostered by the school counsellor. It is felt that wider social issues and political tensions arising from the occupation give rise to some negative behaviours amongst the children and the school is on its guard to deal with this positively. Approaches to teaching and learning in the school are embedded in the school's ethos. The International Baccalaureate (IB) programme is fully operational at secondary level and in the middle years and the school is currently working towards the implementation of the Primary Years Programme (PYP). Ramallah Friends School is the only IB school in Palestine and, as such, offers a fundamentally different pedagogical approach, based on enquiry and participatory, student-centred learning. In addition to this the Understanding by Design (UBD) approach to teaching and learning was introduced in 2012. This takes into account how students learn and seeks to promote understanding rather than rote learning which is markedly different from the traditional teacher-centred approaches typically found in Palestinian schools (Wahbeh, 2011).

The period of my research involvement with FGS was a time of tumultuous change at the school. There was a new head in 2012 and again in 2013, each bringing widespread changes to the pedagogy and organisation of the school. This impacted massively on the teachers and it is to their credit that so many of them willingly embraced the idea of participating in my research. The overwhelming changes taking

place within the school meant that it was difficult for them to participate as much as I or they might have wished. Nevertheless busy as they were, the teachers demonstrated an eagerness to learn and develop professionally. In Palestine not all teachers have a qualification in teaching as it is not a requirement and indeed there are some reservations about the extent to which the training of those who have received it has prepared them for the role, particularly in terms of being able to address the needs of students with differences or difficulties. Initial teacher training does not, in many cases, address the issues of special educational needs.

The Learning Support Department at Ramallah Friends School was introduced as a novel venture in 1995 during a period of renewed stability and hope after the first Intifada. The new Palestinian Authority had just introduced the Ministry of Education. At that time schools did not address special educational needs and children with special needs were kept at home, institutionalised or, in a few cases, catered for by Community-based Rehabilitation Programmes (CBR). From her experience in Jordan, the new Director of Learning Support was convinced that it was possible to include children with diverse needs within schools and fortunately she had the support of the Head at that time to persuade the board of trustees to have a trial year. From the outset, the department worked in an inclusive way in the classrooms, supporting pupils by providing teachers with the necessary skills and using a UNESCO training package (UNESCO, 1993), widely used within the Middle East at that time to promote inclusive approaches for pupils with special needs. Ramallah Friends School stands alone as the only private school in the West Bank<sup>23</sup> that has a learning support department and in the years since the department's tentative

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<sup>23</sup> In the West Bank there are 301 private schools, 1,573 government schools and 97 UNRWA schools (PASSIA 2011)

beginnings it has grown and now has seven Learning Support Teachers and three part-time Teaching Assistants. Most of their work is carried out in the classrooms but they also have a Resource Room with space for certain withdrawal activities. There were about fifty three pupils with special needs within the whole school (FGS and FBS), representing about 4.5% of the school population<sup>24</sup>. The wide range of needs included Downs Syndrome, Williams Syndrome, autism, cerebral palsy, dyslexia, speech and language difficulties, hearing impairment and visual impairment and the school involves and works with parents to address the needs of pupils. There are no external agencies to which the school can turn for advice and support with pupils with special needs. The over-stretched IECs employed by the Ministry do not serve private schools. The Director of Learning Support saw it as part of her role to continue to update and improve her knowledge and understanding, and parents and professionals turn to her for advice and support. Early on, she identified a boy in the kindergarten whom she thought to be on the autism spectrum. Working with parents, the school supported this student through his education and he graduated successfully from the FBS High School not long ago. During the research period there were four pupils, all boys, each with a diagnosis of autism and the school has previous experience of success with two boys on the autism spectrum, one of whom is now undertaking a BA course at the Art Academy.

Perhaps only nine miles away from the Friends School, but in terms of travel for West Bank Palestinians, it might well be nine hundred miles, Amira Basma School, the second, and very different, setting involved in the case study is situated in the Mount of Olives region of East Jerusalem. Although it is nominally a private school, the fees

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<sup>24</sup> This number relates to 2011

are very low. The school prides itself on upholding 'equal opportunities for children everywhere and without any discrimination ..... Not privilege for those who can pay' (Interview PR2). The school is situated on the first floor, above the Princess Basma Rehabilitation Centre, a medical centre for children with disabilities established in 1965. The Centre was inaugurated by Princess Basma, sister of late King Hussein of Jordan. It is a charitable organisation and works under the auspices of the Anglican Church in East Jerusalem. At the beginning it was a home for the many hundreds of physically disabled children afflicted by an epidemic of poliomyelitis at that time. In 1967 it was taken over by the Israelis. Immunisation prevented further cases of polio and the Centre turned its attention to children with other needs such as cerebral palsy, disability caused by accidents, burns and congenital disabilities. It became a rehabilitation centre rather than a care home, with an infrastructure of professionals: doctors, nurses and therapists. Children from the age of 0 to the age of 16 from the West Bank and East Jerusalem are catered for but children from Gaza no longer come because of travel restrictions. Children are admitted with their mothers because running alongside the rehabilitation and treatment of the child, they offer an empowerment programme for the mother. In the 3 to 6 weeks that mother and child stay at the Centre, they train the mother to accept the child, to live with the disability, to fight for her rights. As the main care-giver for the child, the mother learns what to do when she returns home to her community. One positive result of this initiative is that it has helped to create networks of mothers of disabled children who help and support each other in the West Bank. The Centre operates an outreach service, training community workers in West Bank communities. The centre, celebrated for high standards of work in the field of childhood disability, is accredited by the Israeli

Government and has productive liaisons with Israeli organisations in the same field but, in this segregated society, the centre is for Palestinians only.

In 1987 they opened a small school for the children who were attending for rehabilitation. This expanded and is now known as Amira Basma School. From small beginnings, the school grew until there were children of all ages and the school began to accept non-disabled children from the local area to learn alongside the children with a wide range of disabilities. From the outset the school has operated a policy of 'inclusion' and in the main children with special needs are placed alongside their typically developing peers. There are however some classes for children with SEN. Altogether in a school population of 830, there are 150 students with special needs. It is the only school in the area which includes children with special needs alongside typical children and there are said to be good relationships between the two groups. The Deputy Head who oversees the day-to-day running of the school, is a strong believer in working for social equality within the school and strives for greater flexibility within the curriculum to allow children to develop their own areas of interest and develop as free-thinking human beings. The school currently offers what is primarily the Palestinian curriculum but this is a growing area of difficulty with the Israeli authorities who wish to see an Israeli curriculum at the school.

In recent years the Amira Basma Rehabilitation Centre, situated below and separate from the School, has worked towards addressing the needs of children with unseen disabilities, and in September 2011 they opened a small centre for young children with autism. It is the first of its kind in Palestine and staff are rightly proud of this initiative. It is seen as an education and treatment facility and is located on the

ground floor, near to the medical centre and, at the time of writing (2012), had five children aged three years old, with two teachers and four therapists who underwent extensive training in the year before the centre opened. An occupational therapist and a speech therapist share responsibility for running the unit. The autism unit was started in response to an increasing number of children for whom there was no provision. Funding for three years was secured from the European Union until the end of 2012 by which time they hoped to be fully accredited and financed by the Israeli Ministry of Education.<sup>25</sup> Parents do not pay for their children to attend and the current cohort of children was selected on the basis of being 'more able' in order to give the unit a better chance of a successful start. In the future they plan to include children whose autism affects them more profoundly.



Figure 36: Sensory Room at Amira Basma Autism Unit

To help with implementation of the autism unit the Sawa school in Nazareth provided valued training and regular support and monitoring. Key staff also visited Sweden for training in Applied Behavioural Analysis (ABA) and Picture Exchange Communication System (PECS). However, they found that ABA was not for them as they find it too rigid, 'robotic', and not about developing communication (Interview PR1). They prefer

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<sup>25</sup> The autism unit is now accredited and funded by the Israeli authorities

to use a range of approaches including TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children), AAC (Augmentative and Alternative Communication) and the DIR approach (Developmental, Individual difference, Relationship-based). They also have an impressive Snoezelen room (controlled sensory environment) for which they bought equipment in London. They are committed to working with parents and teaching them strategies to support their children's development. Children in the autism unit are all from East Jerusalem as daily travel is not possible for West Bank children. The EU funding also enabled staff to undertake an outreach programme in the West Bank with communities in Nablus, Ramallah, Jericho, Hebron and elsewhere. The aim was to work with centres that have children with autism and help them to set up specialist provision.<sup>26</sup>

## **7.2 Initial questionnaire – Friends School**

Research at Friends School began in October 2011 with a questionnaire (Appendix 1), translated into Arabic, to probe attitudes, knowledge and experience relating to SEN, inclusion and autism. All staff were invited to complete it and twenty seven (50%) did so. The results give a picture from which it is difficult to draw clear conclusions, not only because of the 50% of missing responses but also because of the 50% of responses I did get. The questionnaire raised more questions than it answered and led me to ponder on its usefulness as a research instrument. I could probably double the length of my thesis with in-depth analysis of the questionnaire itself: the lengthy thought processes that led to its creation; the relative merits of the closed and open questions; the piloting of it and redrafting; the important issue of translation of the questionnaire, leaving me uncertain to what extent my precisely

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<sup>26</sup> Update 2013: I understand that funding for this work has now ended.



chosen wording had been replicated in Arabic; the translation of the responses back into English which raised the same question on behalf of the respondents; the cultural aspects of using a questionnaire – how might the respondents have felt about being asked to complete it; the issuing and collecting of them on my behalf while I was back in the UK. The number crunching and presentation of data (Appendix 16) was the easy bit. However, a lengthy analysis of the questionnaire itself has no useful place here as it would not address my research questions. My reflections on this research method however were part of my research journey. I was able to see how the questionnaire lacked the dynamic flow of the semi structured interviews that I had used in data set 1 and had strait-jacketed responses into the limited number of tick boxes. Although I allowed space for open responses to questions very few people took this option. I was left feeling that the data I obtained ill-fitted my wish for an interpretative approach as I was left not knowing how the respondents felt about their answers or how much consideration they had given them. I was nevertheless able to learn something from the experience and develop my research skills so that when I came to devise the questionnaire for the Ministry of Education workshop, discussed previously, I kept it very simple, with few words and only three open questions and this proved more productive. So although I had hoped for more useful answers to my research questions, the deficiencies I have described are mine, not theirs. There follows a discussion of what I found from analysis of the staff questionnaires at FGS. Data from the questionnaire is presented in 8 bar charts in Appendix 12.

Question one sought to find out what support was available to staff when they had responsibility for a child with particular needs such as autism. I had been told that the

school did not have access to specialists for advice and I wondered where staff might turn. 74%, the biggest response number, indicated that they would ask the child's parents for advice. It was interesting to see this correlation with the data from data set one which also found that, in the broader context of provision within the community, parents were seen as important partners in supporting the child. A sizeable number (over 40%) indicated that they would turn to the Internet for advice, raising questions about the advantages and dangers of on-line searches, but I did not ascertain whether this was a useful source of information for those who chose to seek information in this way.

My second question asked whether respondents had experience of working with a child with autism. The 48% positive response rate surprised me as there were only 4 children with diagnoses of autism in the school. However, pupils do move between subject specialists within the school and it also seemed possible, or even likely, that the 50% of staff who had returned the questionnaires were also the ones who were most interested in the research as they were the ones who worked with the children with autism. What I did not get from the data was how much experience they had had or their perceptions of this experience. Data from the Ministry workshop (data set 2) had suggested that very few children with diagnoses of autism attend government schools so it is unlikely that this response would have been replicated with staff in a government school, had I been able to recruit such a school for my research.

Thirdly, I asked whether the respondents had had the opportunity to learn about autism. 16 (59%) indicated that they had done so; 6 during their initial teacher training, 7 during INSET courses and 3 in a combination of both. I had no means of knowing the depth of knowledge that this had given them. The result was very

surprising as other data indicated that professionals did not have any opportunity to learn about autism (data set 1; Table 16, p.149) and a member of the special needs team at the MoEHE had told me that 'initial teacher training does not include SEN, and certainly not autism' (M1). I have been unable to make sense of the reason for this conflicting data. Perhaps some of them had done their initial training abroad. The INSET can perhaps be explained by the commitment the school had to supporting children with autism and the fact that the knowledgeable Learning Support Director had received substantial training abroad. I was unable to clarify this. Although this does not correlate to findings from other data sets, it does correlate to data from question five in this questionnaire where respondents were asked about their depth of understanding of autism; here, most staff felt that they had at least a little knowledge about autism. 63% indicated 'know a little'; 22% indicated 'knowledgeable' and 11% indicated 'very knowledgeable'.

Responses to question 4 showed a strong opinion in favour of the inclusion of children with autism. 82% 'strongly agreed' or 'agreed' with the statement that 'children with autism should be included and taught alongside their typically developing peers'; two people were neutral, one disagreed and two did not respond to this question. This correlates with findings elsewhere of a positive attitude towards the notion of inclusion. However it does not indicate the respondents' notion of what inclusion is.

The next pair of questions (6 and 7) were included to enquire how well staff felt their training had prepared them for working with the average child (Q6) and the child with autism (Q7). Not everyone answered: there was a 66% uptake for the first of these

questions and 81% for the second. The data was surprisingly similar for each of these responses. Figure 37 shows the response to the questions: how well did your training prepare you to work with the 'average' child (light grey); and how well did your training prepare you to work with the child with autism (dark grey). I was surprised to see how well prepared the respondents felt to work with the child with autism and, conversely, how ill prepared they felt they were for the 'average' child. My reading had given me a sense that teacher training was insufficient (Khaldi & Wahbeh, 2002; Nicolai, 2007; Khalili, 2010) and this was backed up by findings from the interviews suggesting that *'another big problem... is the pedagogy we have; it is very traditional [and] didactic'* (T1); and, *'the teachers come from educational institutions with no training at all, not only in dealing with children with SEN, but in education in general sometimes'* (T1). Also in the MoEHE workshop it was felt that in general *'there is a lack of expertise and training for educators at all levels'* (data set 2 p.186). But it was surprising to see how well prepared they felt to work with children with autism in the light of what I had learned from the contextual enquiry. However, FGS is unique in its inclusion of children with autism and undoubtedly staff were in a better position to be confident in their ability to work with autism.

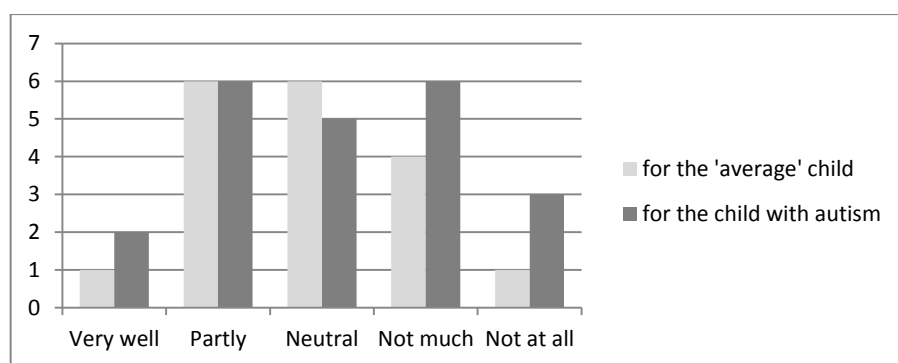


Figure 37: How well did your training prepare you to work with the child with autism? (FGS)

The final question (Q8) boded well for my research as there was a strongly positive response to the statement: 'I would like to develop my skills and knowledge for working with children on the autism spectrum'. No-one disagreed and only one remained neutral, leaving 96% who agreed or strongly agreed with this statement.

### **7.3 Setting up and working with the focus group – Friends school**



Figure 38: Friends School focus group

In October 2011 I held a workshop with all teaching staff to introduce the research, to identify those who might like to be involved and to talk about autism and notions of good practice in education. After that, twenty four teachers attended a meeting to form a focus group of participants. Members of the group completed a participant consent form (Appendix 3) to indicate that they understood what was involved and their right to withdraw. They were asked to provide information about their experience, knowledge and wishes in relation to the research topic. During the course of the research numerous meetings and discussions took place with members of the focus group, sometimes individually, sometimes in small groups, sometimes all together. Meetings were sometime face to face and sometimes, when I was back in

the UK, by Skype. As well as the initial workshop there were also two further workshops involving all the members of the focus group, a changing cohort, to think about some of the issues that had been raised within the smaller groups. These workshops were interactive and involved case studies designed to reinforce and generalise the practical issues that we had looked at. In addition, a further shared workshop was held, together with participants from the Amira Basma Centre. An overview of the research activities at FGS is shown in Table 34.

Record of research activities at FGS		
Date	Details	
Prior to first field trip in October 2011	Skype interview and numerous email exchanges with Head of Learning Support who is the key link person for the project	
	Formal letter of introduction to the (then) Acting Principal	
	Questionnaires to all staff (analysed)	Appendix 1
	Information sheets and participant consent forms to all staff	Appendix 3 + 4
	Information sheets and participant consent forms to the parents of children on the autism spectrum (4)	CD:C1 / CD:C3
Fieldwork October 2011	Planning meeting with Head of Learning Support	
	Interview with Deputy Principal (recorded)	CD:D1
	Classroom observations of three pupils on the autism spectrum (Pupils 1,3,4)	CD:H9
	Individual interviews with three mothers of the three pupils (recorded)	CD:D4
	Workshop for all staff including Learning Support Teachers from the Boys' School	Plan and materials
	Focus group meeting with staff who wish to participate in the research project. (attended by over 20 staff) Initial discussion about targets. (20.10.11)	
	Informal discussions with numerous members of staff	Field notes
November 2011 – March 2012	Friends School Focus Group questionnaires - translated and collated	CD:C7 / CD:H5
	Transcribing Interviews	
	Developed WIKI – PALAF (ongoing)	Online
	Letter to members of Friends School Focus Group (Rasha translated)	
	Skype meeting (2) with Focus Group. – target setting (observation and assessment); Introduced WIKI	
	Skype with Head of Learning Support	

	Skype Meeting (3) with Focus Group - Evaluation of the Assessment Profile	CD:H11 /CD:H12
<b>Fieldwork March –April 2012</b>	Classroom observation of pupil (pupil 2)	CD:H9
	Meetings with the four smaller focus groups linked to the 4 students.	
	Meeting with parent 3	
	Workshop	Plan / materials
<b>April – October 2012</b>	Skype meeting with focus group (May)	
	Skype meetings with Head of Learning Support (25.9.12) and colleague (18.9.12)	
	Evaluations of the Assessment Profile – translated and collated Assessment Profiles –translated	CD:H11 /CD:H12 CD:H10
	Skype meeting with Focus Group (11.10.12)	
<b>Fieldwork October / November 2012</b>	Karen Guldberg and I meet Head teacher	Field notes
	Workshop for Focus Group teachers	Plan and materials
	Meeting with a Focus Group (select group)	Field notes
	Meeting with parent 2	Field notes
	Planning meeting with Rana	
<b>November 2012 – April 2013</b>	Final questionnaire – devised, translated and issued	CD:C8
	Adapted and sent IDP for Rana to use with teachers	Materials
	Planning skype with Rana	
	Returned final questionnaires translated and collated	CD:H16
	Skype with FG teachers about pupil 2 (4.2.13)	
	Skype with FG teachers about pupil 4	
	Devised and sent materials for teachers to try out. (This happened throughout the research period)	Wiki Table 39
	Skype meeting with Rana	
	Exchange visit – 5 FG teachers visit ABC	Field notes
	FG teachers write stories about their work	Table 40 / CD:C12
<b>April 2013</b>	Meeting with parents (x3) (Parents 2,3,4)	Field notes
	Classroom observations of 2 pupils (Pupils 4 and 2)	Field notes
	Shared workshop with Amira Basma	Plan, materials and report

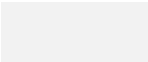
 = fieldwork in Palestine

Table 34: Research activities at FGS

The nature of the focus group was not without its challenges. I was encouraged by the positive response and the unexpectedly large number of staff who wanted to participate as I had anticipated a small focus group. I was delighted by their friendliness and the warm welcome they gave me. I did not want to turn anyone away in the interests of having a more manageable group. After all, this was about inclusion and I certainly did not want to start off by excluding people. The size of the group, however, made it impossible to get everyone together during a working day but this was not the only challenge. Staff were tired and unsettled by the big changes to their working practices, as I have mentioned. I was only in Palestine for two weeks every six months, so there was a significant limit to the continuity of our working together and there were often insurmountable technological difficulties in using Skype to stay in touch as the internet connection was poor. Continuity of the work was challenged by the fact that the staff working with the children with autism changed from year to year, so that the membership of the Focus Group also changed; new people came to the school and wanted to join in and others departed. As well as this, the Director of Learning Support left to take up another post and although she continued to be highly supportive of the research, as indeed did her replacement, this nevertheless meant a significant break in continuity, and a gap between me and my closest ally. Despite challenges, there were notable opportunities to learn from working together, as I will show, and participants in the Focus Group demonstrated enthusiasm, willingness to learn, genuine interest, openness to new ideas and real care for the students.

In Chapter Five, I mentioned the tensions inherent in my role. Participants, with their experiences of Palestinian pedagogy perhaps expected a more traditional



relationship between us of passive learner and authoritative teacher, as further illustrated in my field notes (Table 35).

Extract from field notes (4/12)
Today I met with N***** to discuss a child with autism in her class. She arrived with notebook and pen at the ready for me to tell her what to do. I could not give her the recipe she was expecting. What we needed to do was more like sitting down together to do a jigsaw puzzle: she had some of the pieces (knowledge of the child and the school culture), I had some of the pieces (some knowledge of approaches that had been found to work elsewhere) and we would need to search together for the remaining pieces.

Table 35: Extract from field notes (4/12)

I intended the reseach to be a collaboration, not about me telling them what to do. It was an unresolved tension in the research that I was perceived as an ‘expert’ from the UK, so that teachers sometimes came, notebook in hand, for me to give them the recipe. Some of them had previously met me, before the start of my research, when I ran workshops for QCERD, and so it was not perhaps surprising that there was this ambiguity about my role. I return to this exploration in the final chapter when I consider the communities of practice model as a means of sharing and harnessing knowledge and empowering groups of people who are interested in developing autism practice.

In the early days of the research the four students with autism became central to discussions and shaped the development of the way we worked. We focussed on things that were of practical value to the teachers of these particular children in a changing and evolving situation. The four boys developed over time and this part of the study was of practical relevance and also gave an opportunity to consider what was useful in this particular school in Palestine. The teachers were willing for me to observe classes where there were children with autism as this gave us a good basis

for working together. Classroom observations of the four boys enabled me to look at environmental features, pedagogic style and the nature of learning activities using an Observation Nudge Sheet (CD:C9). In this I was supported by my translator who used Observing Pupil Communication (CD:C10) devised by me, based on SCERTS Assessment Process (Prizant & Whetherby, 2006). We discussed and made a written record of our observations after the event, giving a basis for fruitful discussions with the teachers shortly afterwards. Analysis of the observations (CD:G10) offered themes that were of interest to this research in terms of the classroom environment, pedagogy and teacher style of interaction, and in terms of autism friendliness of the environment. In the main I saw busy purposeful classes with mixed-ability students engaged with their learning. Students were grouped around tables, rather than the more traditional sitting in rows. In half of the classes students worked individually, facilitated by teachers who circulated between groups. In the other half of the observed classes there were whole-class question and answer activities and remnants of a more didactic teaching style. All classes had Learning Support Teachers who circulated between groups and, in one case, was solely attached to one student. There were no observed IT resources in the classrooms. Three of the observed classes were felt to be in cramped, crowded classrooms. Teachers were often warm, friendly and encouraging to students. Teacher style of interaction, in three cases was very loud and they shouted to gain attention. In one case the child with autism had his fingers in his ears when the teacher talked (FN 10/11). The observations prompted me to think about the ways in which the classes I saw might be considered to be 'autism-friendly'. An extract from my field notes is given below in Table 36.

Extract from field notes (10/11)	
<p><b>Autism-friendly factors that I observed</b></p> <ul style="list-style-type: none"> <li>• Strong relationships with pupils with autism, both between staff and pupils and with peers</li> <li>• Teachers are patient and create a positive environment where children feel comfortable</li> <li>• Some use of individualised visual supports (but not always apparent)</li> <li>• Structured activities in most cases</li> <li>• Individual support is given to help understanding and engagement with learning</li> <li>• Pupils with autism are included alongside their peers</li> <li>• Some evidence of flexible approaches to differentiate the learning activities in order to support a child with autism. For example, the use of a CD player, headphones and disc to allow a pupil to follow audio text version of the lesson on his own</li> <li>• Staff get to know the individual child and what works best for him</li> </ul>	
<p><b>Things to consider:</b></p> <ul style="list-style-type: none"> <li>• Classroom noise and teacher shouting to gain attention may be difficult for children with hypersensitivity to noise</li> <li>• Children with autism are not always cued in to listening when the teacher is talking to the whole class</li> <li>• Pupils with autism may need to have individualised instructions</li> <li>• Visual timetables and schedules could be used more widely and would be valuable</li> <li>• More flexible teaching approaches may be needed</li> <li>• Fluorescent lights can be significantly distracting for some children with autism</li> <li>• Children who process verbal information slowly need more time to think</li> <li>• Reducing the amount of spoken language used may help children with verbal processing difficulties</li> </ul>	

Table 36: Extract from field notes (10/11)

From the observations I also gained a snapshot view of the four pupils which then served as a basis for discussion with the teachers in the focus group and as a starting point for thinking about developing practice. My records noted observed behaviours which could be used to identify possible strengths as well as difficulties and on the basis of this I held pupil-focussed discussions with teachers who knew the child best. The teachers, I found, were already predisposed to consider the child's strengths and interests, not just to think about him in terms of deficits and problems.

The emergent nature of my research design and the reality of working in a dynamic and complex situation resulted in an on-going cycle of action and critical reflection. What evolved was a series of extemporised responses to the needs and questions

raised by the group, devising approaches to deal with specific issues such as: Yousef is distraught if he makes a mistake; Rami runs off and has no sense of danger; Sami upsets his classmates by taking their things without asking; Ahmed does not play with other children. The focus was practical and the four boys were central. Figure 38 illustrates how the case study / action research developed. As the diagram shows, the work evolved from initial planning (top left) to final questionnaire (bottom right) following the winding path of arrows. It illustrates how the pupils held four focal points of iteration that were central to the research. The diagram also captures the four workshops, spaced throughout the research period and it indicates how material that was developed fed into the Wiki resource bank that we created.

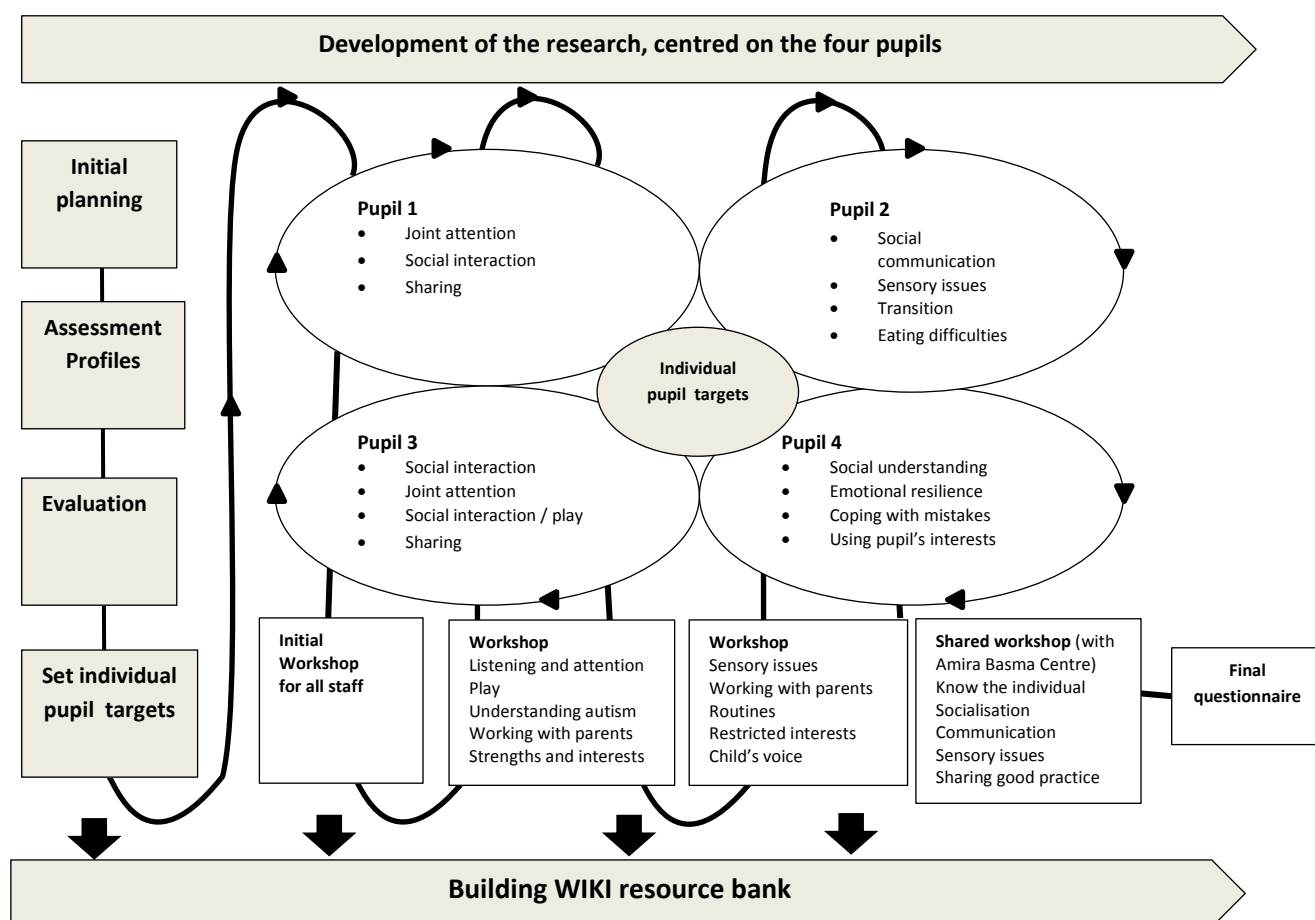


Figure 39: How the Case Study / Action Research developed

The Focus Group teachers undertook their own observations and assessments of students with autism as a first target. This practical activity would highlight the importance of observation and understanding, raise awareness of many characteristics of autism and underline the importance of identifying strengths and interests and well as difficulties. For this I designed an assessment profile based on the SCERTS model (Prizant & Whetherby, 2006) for them to try out (Appendix 6). The profile was used to observe the pupils with autism, assess strengths and difficulties and identify key areas to be targeted. In addition there was a sensory checklist translated from the Inclusion Development Programme materials and based on the sensory profile checklist from Bogdashina (2003) (CD:H17). Evidence from the evaluations shows that teachers found the profiles valuable (Tables 37 and 38). Teachers also suggested ways of improving the profiles.

<b>Teachers' Comments about the Assessment Profile</b>
<b>'The profile helps to understand him better as a person and how he communicates with others. Also, how to deal with him to help him to integrate socially'</b>
<b>'We now understand the student better'</b>
<b>'The activity was comprehensive and valuable'</b>
<b>'It would provide useful information for the new teacher'</b>
<b>'It would help with the parents and make staff look more professional, so building the parent's confidence in us'</b>
<b>'Made us think more about his social development'</b>
<b>'As teachers we start noticed some new things'</b>
<b>'We know (pupil's name) better now'</b>
<b>'It was valuable, it helps us to understand the differences between students in general and autistic children in particular'</b>

Table 37: Evaluation of the assessment profile

Teachers' Comments about the Sensory Profile
'Helps in understanding the ambiguity in the child's character'
'It developed understanding of the child's sensory needs'
'Made us realise how different they all are'
'The sensory profile is difficult for the teacher to complete alone and perhaps would be better to give it to the parents'

Table 38: Comments of the sensory profile

The teachers found, in the words of one of them, that it was '*difficult gaining the student's perspective*'. I had raised the issue of seeking the views of the child and had discussed ways of doing this as good practice in autism involves listening to the voice of the child (Parsons et al., 2009; Charman et al., 2011; Hesmondhalgh, 2006). However, I formed the impression that this was a novel concept for the teachers here and that there was resistance to actively seeking out the child's voice within this activity. Evidence from the evaluation of the assessment profile showed that not one of the four groups attempted to elicit the pupil's views. There may be cultural aspects at work here, where dialogic approaches to teaching are not common, that render the notion of eliciting the child's voice a novel concept with which teachers feel uncomfortable. This is an area that would be worthy of further research and is one that I return to in the final chapter.

Having completed the Assessment Profiles on the four pupils each group of teachers, in self-selected groups based on which child they were most involved with, identified two areas to work on with the student they observed. These were:

- Group 1: Social interaction; Joint attention
- Group 2: Social communication; Writing process
- Group 3: Joint attention; Social relationships
- Group 4: Social development; Emotional resilience

Over the period of the research, skype and face-to-face meetings with members of the focus group, were held on 18 occasions (Table 29) to discuss the needs of the four individual pupils. We discussed strategies and approaches for working with the four pupils with autism and in most cases this was supplemented by an addition to the resource bank on the Wiki. Working in small groups made it more possible to bring the groups together and overcome the difficulty of having too big a group. The teachers were proactive in developing and adapting strategies and approaches to use with the pupils (Table 40).

#### 7.4 The Wiki

The Wiki (Figure 13) was developed as an online community space for participants to share. It enabled me to provide resources in response to requests and discussions and in many cases these resources were translated by the translator and posted in both Arabic and English. It also gave members the opportunity to post information although this opportunity was not taken up. 25 out of the 42 people (this number includes staff from both settings) who were invited to join the Wiki did so. The Wiki was used by very few people and it seems likely that the Wiki would have been far more useful if it had been more user-friendly and information all in Arabic. Two of those who used it regularly were the translator / assistant and myself, making the uptake 35%. Nevertheless, it holds a valuable record of the areas of interest at FGS that were explored during the period of the research (Table 39).

Materials devised during the research and placed on the Wiki
<ul style="list-style-type: none"> <li>• Observation and Assessment of students with autism (in Arabic)</li> </ul>
<ul style="list-style-type: none"> <li>• Sensory issues (in Arabic)</li> </ul>

• Listening and attention (in Arabic)
• Examples of visual schedules
• Visual prompts for listening
• Emotional regulation and coping with mistakes
• Eating difficulties
• Strategies for encouraging social interaction
• Play
• Social Stories <sup>®</sup> to promote social understanding (one example in Arabic)
• Example of a Social Story (in Arabic)
• Inclusion
• Transitions
• Handwriting and writing skills
• Peer awareness
• Autism and the way you can help (in Arabic)
• Autism: strategies for young children (in Arabic)
• Obtaining children's perspectives
• Pupil Passport ( to support transition and self awareness) (in Arabic)
• Comic Strip Conversations
In addition the Wiki has:
• Minutes of meetings (Arabic)
• Current publications (eg Inclusion Development Programme for autism)
• Websites
• Three documents in Arabic (from Lebanese Autism Society)

Table 39: Examples of materials devised and placed on Wiki

My research was not a dispassionate study for the purpose of writing a PhD thesis; I hoped that the Wiki would provide a lasting resource that could continue to grow after the research period, and so the lack of uptake by the participants was disappointing.



There are lessons to be taken from this setback, however, and some ideas that I would offer to others undertaking such a venture. Firstly, it seems likely that it would have been useful for the construction of the Wiki to have been a collaborative venture, negotiated, discussed and designed with those for whose use it was intended. I did make the suggestion early on and asked for people to work with me on it but when there were no takers, and under pressure of time, I went ahead, learned how to make the Wiki and gave them a *fait accompli*, so that the ownership was then mine and not shared. Secondly, although some contents were translated into Arabic, there were also documents in English and links to English language websites and the operating language was in English. This could have been a disincentive for busy people who did not have good English. I did contact PB Works, the providers of the Wiki that I used, to ask about using dual languages and whether anyone had experience of this, but they, at that stage at least, had no advice to offer. We put dual instructions in both languages on the opening page, but that made it cluttered and less readily communicative. I needed it to be in English too, not just Arabic, so that I could access it, but the complexities of providing a dual language online environment for us to work together were beyond the level of skills that I had time to acquire. Another thing, I had made an assumption that everyone had access to a computer and the internet, and I was encouraged in this belief by the responses to the initial questionnaire which found that 40% of the staff would choose to use the internet to research the special needs of pupils. However, I did not know whether everyone in the focus group had this facility or whether it was an environment which which they felt comfortable. Subsequent experience of difficulties with internet connectivity for skype and email during the course of the research raise the

possibility of difficulties in that regard. Had time allowed, a feasibility study and a preliminary study of the design features that would be most useful, culturally appropriate and user-friendly would probably have been valuable. Perhaps there is the opportunity in Palestine to create a more useful online knowledge-sharing environment for, and crucially with, those who are interested in the development of inclusive approaches for children with autism. Findings from the contextual enquiry had indicated lack of access to information and resources, the isolation of parents and the absence of shared endeavour and the Wiki was an opportunity to think about how this gap might be bridged by online technology. This is another issue that I return to in the final chapter. Nevertheless, the Wiki holds a record of the resources that were useful (Table 39), and, in the Palestinian context where financial resources are limited, it is a reminder that many approaches and resources that can be used to support the education of children with autism are not costly.

A record of the work of the focus group teachers is preserved in stories (Table 40) they wrote about their practice with autistic students, illustrating growing awareness and giving evidence of approaches for working inclusively with children with autism, successful or otherwise, in this particular Palestinian school. The headings and the words in square brackets are mine and names have been changed. The stories often illustrate practices that would be useful for any pupil but for children with autism they can be essential for them to be able to cope in a school environment. After each story I have included a short bullet point list to indicate aspects of good practice.

Stories from Friends School
<p><b>Encouraging friendship and social interaction.</b></p> <p>'We [like to] find a common hobby between the child with autism and his class mates to help them to be friends and to build a trust relation between them. Yousef loves matchbox toys so we took permission from the deputy head teacher to be able to ask his parents to bring matchbox toys in to school, as it is not allowed for kids to bring toys to school. There is a boy in Yousef's class who loves Yousef but he sometimes gets a little bit bored because he can't share all his interests. [He told me that] he loves matchbox toys too, like Yousef. So we kept the toys in school and whenever he found Yousef in a bad mood or feeling left out of the group because he couldn't follow the games that the others were playing, he would play with him with the matchbox toys'.</p>
<ul style="list-style-type: none"> <li>• Flexible educational approaches / adapting what you do</li> <li>• Building relationships with peers</li> <li>• Building on child's interests</li> <li>• Allowing solitary quiet time when needed</li> </ul>
<p><b>Using the child's interests</b></p> <p>'[We found it valuable to] use the student's interest in the academic procedure [motivating them in their school work]. For example Ali is a child who likes the different countries and likes to travel, so we used this interest to make different exercises sheets in different subjects using the different places and the Archaeological places there. In collaboration with his teacher we decided to make a worksheet about other countries. It was very interesting for the other student as well. He did great in reading the stories and answering the questions.</p> <p>We also made stories for him about his family holiday in Paris. I talked to his mum and she gave us some pictures from the holiday, like of the Eiffel Tower, and we wrote stories for him. We also used the stories to relate them to his feelings for him to learn about feelings'.</p>
<ul style="list-style-type: none"> <li>• Using child's interests</li> <li>• Collaboration between colleagues and with parents</li> <li>• Flexibility</li> <li>• Teaching about feelings</li> </ul>
<p><b>Role-modelling</b></p> <p>'Khalid used to cry if he did something wrong. We decided with his teacher that she would [deliberately] make mistakes sometimes and then she would say, "I made a mistake but it's OK. We can find different ways". It was a good thing to try but I still think he worries and doesn't like to make mistakes. It hasn't made a huge difference for Khalid but it may help other kids in the class or other kids with autism [to deal with making mistakes], but for Khalid he is still a perfectionist. But he is progressing a bit. We also tried Social Stories [with this issue] but they didn't interest him much. [Whereas] another boy, Ali, [responds well to Social Stories and] gets very excited. He wants to read it, take it home, read it with his parents and his friends. But for Khalid it didn't grab his attention'.</p>
<ul style="list-style-type: none"> <li>• Accepting that approaches don't always work and you may need to try again (no recipes for success)</li> <li>• Knowing and understanding the child</li> <li>• Using visual approaches such as Social Stories to develop social understanding</li> <li>• Flexibility</li> </ul>
<p><b>Using Visual Supports</b></p> <p>'We always use visual supports with Omar and Yousef. We use them a lot. Yousef has photos for all</p>

<p>his classes on his timetable. When there are any changes to the class we also use visual supports [so that he knows what is happening]. We use visual steps [schedules], and we gave them to his mother too, for changing clothes, eating, using the toilet and the bathroom. In the classroom there are visual supports everywhere, made by the teachers and the Learning Support Department.</p> <p>[There used to be] a problem with Omar. Once a week all the students meet in the chapel [for assembly] and he had difficulties with that and he refused to go there. I made a visual schedule for him about it. It took him some time to adapt but it was very useful'.</p>
<ul style="list-style-type: none"> <li>• Using visual timetables to promote understanding and reassurance for child with autism</li> <li>• Sharing strategies with parents</li> <li>• Flexibility and individualised approaches</li> </ul>
<p><b>Comic Strip Conversations</b></p> <p>'[We used this strategy with] Ali when he used to hit someone or take their things from them. I took a sheet of A4 paper and I would draw [a stick figure to represent] the person that he hit. Ali would say what he did and what he said, and would draw that [too]. He would say why he hit him and how he felt. Then at the end he would tell me how he feels about it now. We used to talk about his feelings and also about the other student's feelings. It seemed to help for that day but another day he might continue doing the same thing'.</p>
<ul style="list-style-type: none"> <li>• Using a visual approach such as Comic Strip Conversations to promote social understanding and</li> <li>• Evaluating the success of approaches</li> <li>• Promoting self-awareness and teaching about feelings of self and others</li> </ul>
<p><b>Encouraging Sharing</b></p> <p>'You have to find a different way to deal with each student. There is a child, Omar, who loves the swing, and refused the other child to play with it. We taught him that he has to allow the other children to play with the swing. I started using a timer and talked to him to explain that other children were waiting. I said, 'You have 2 minutes. The other student is waiting.' At the beginning he refused and started crying. I helped him to look at the other student and to see how happy he was to have his turn on the swing. Eventually he came to understand that there are others who want the swing, the same as him. Eventually at the end of the year we could just tell him without using the timer that it was another child's turn. You know other children love him so much and he feels that. They used to say, 'It's ok. Let Omar keep the swing', but, 'No,' I used to tell them, 'You have the right to play on the swing and Omar needs to learn that there are others who want to play on the swing too. We have some lovely students'.</p>
<ul style="list-style-type: none"> <li>• Promoting awareness of the needs of others</li> <li>• Encouraging child with autism to be less rigid in their thinking and behaviour</li> <li>• Using a visual approach (the timer)</li> <li>• Helping peers to understand how to support the child with autism</li> </ul>
<p><b>Support for Transitions</b></p> <p>'At the end of each year I ask [the person who does the timetables] to place students with autism with specific teachers who understand the children with autism and who are more tolerant. I did this with Yousef and I also introduced him to the other students who will be with him next year. We did this with Ali and Khalid the year before and it was very useful'.</p>
<ul style="list-style-type: none"> <li>• Providing additional support for transitions as they can be difficult for the child with autism</li> <li>• Adapting the environment</li> </ul>

<p><b>Building on a student's strengths</b></p> <p>'We had a project about the angles and geometric shapes. Omar [has very good skills on the computer and so he] collected the data [and presented it] by using Power Point, then he presented it in front of his class colleagues. He explained the lesson and smiled then finished the by using "The End" sentence. His colleagues clapped, so he said "The End" again to have another clapped [round of applause]. After that he put his shoulder on mine and smiled. When we finished the class he went out and played. This was a great way to build his self-esteem and contact with the other children by using his strengths'.</p>
<ul style="list-style-type: none"> <li>• Building on pupil's strengths and interests</li> <li>• Finding opportunities to build self-esteem</li> <li>• Promoting interaction between peers and the child with autism</li> </ul>
<p><b>Finding what works for the individual student</b></p> <p>'When Omar [made a mistake in his writing and] wrote a wrong word or sentence and I tried to delete it he became nervous and refused to continue his writing. Sometimes he cried. Then I tried to help him by using some lovely [kind] words and hugging him. [When I thought about it] I recognized that this thing, [interrupting his work to make corrections] harasses him, so I tried another way which is not to delete the words or sentences except after a period of time and when his mood is OK'.</p>
<ul style="list-style-type: none"> <li>• Understanding the individual child</li> <li>• Flexibility - adapting what you do to suit the needs of the child</li> </ul>

Table 40: Stories from Friends School

In the above account of the research at FGS I have tried to convey the richness of the work that was undertaken as well as the many challenges. Despite challenges, there were notable successes in working with children with autism, as illustrated by the stories and it is pertinent to ask what it was that enabled the school to achieve this level of success. A number of factors can be identified.

To start with, at FSG there is a strong emphasis on building positive relationships between staff and students and between the students with autism and their peers. Within this supportive context, students with autism learn alongside their peers and have additional adult support when needed. Visual strategies are used to support understanding for students with autism, and indeed for many other students, and there is a move towards flexible child-centred teaching styles and away from more

traditional and didactic approaches. Pupils with autism are fully included alongside their peers, and teachers hold a model of inclusion which is about using flexible approaches and adapting teaching styles to suit the needs of the individual. They have embraced the value of observation and assessment in planning how best to support the child and readily consider the importance of the child's strengths and interests rather than focussing solely on difficulties. The medical model of disability, whereby a child with autism might be seen as having deficits in need of fixing, is a model that is openly rejected at the Friends School, under the leadership of the head of learning support. Instead, the child with autism is seen as having unique and valid differences that we need to understand and work with. There is a strong ethos of working with parents to support the child, and teachers have embraced an eclectic approach towards meeting the needs of children with autism. There is a readiness to learn about how best to work with children with autism and, indeed, the majority of staff who participated in the focus group (75%) wished to have the opportunity to learn more about good autism practice.

The next section looks at findings from the second setting involved in the case study.

### **7.5 Initial Questionnaire - Amira Basma Centre**

Staff completed the same initial questionnaire as at FGS. The questionnaire was issued to 47 members of staff from the school and the autism unit, and was returned by 24 (51%). Respondents included therapists and teachers who worked in the autism unit, although I was unsure how many. The findings from this questionnaire (Appendix 17) are discussed and summarised here.

Parents were seen as a major source of information (41%) although not as high as at FGS. 16% of respondents had experience of working with children with autism which was surprisnly high. 38%, had received some training relating to autism either initial teacher training or in-service training. 62% had not had the opportunity to learn about autism. Almost half the respondents (45.8%) disagreed or strongly disagreed with the statement 'Children with autism should be included and taught alongside their typically developing peers', whereas eight (33%) people agreed. Many staff (45%) said they had no knowledge or little knowledge about autism whereas only 12.5% felt that they were knowledgeable.

Staff were asked to what extent their training had prepared them to work with the 'average child', and also with the child with autism, and the results (Figure 40) showed that three people felt well or partly prepared to work with children with autism. Staff in the autism unit had undergone a significant amount of training and so it seemed likely that they were the ones who felt most prepared. A surprising result was that only eight of the 24 respondents felt well prepared (one) or partly prepared (seven) to work with the 'average' child. This lack of confidence in their professional skills was an interesting finding for my research suggesting that teachers at ABC were less confident about their teaching than those at FGS.

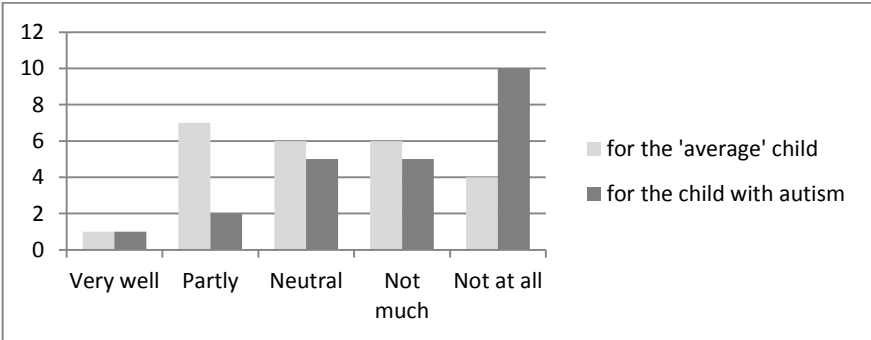


Figure 40: How well did your training prepare you to work with the child with autism? (ABC)

There was strong support in favour of having the opportunity to develop skills and knowledge for working with children on the autism spectrum: In response to the statement 'I would like the opportunity to develop my skills and knowledge for working with children on the autism spectrum', 91% agreed or strongly agreed whereas only one person disagreed.

There were distinct differences between the responses from the two settings. It must be remembered that these surveys took place at the beginning of the participants' involvement and it is arguable that the same questions asked now would produce different results. A brief comparison between questionnaire findings at the two settings shows that a greater proportion of the FGS teachers had experience of working with children with autism (48% as opposed to 15% at ABC). Likewise, fewer staff at FGS indicated no autism-related training (40.7%) whereas that figure was 61% for ABC. Consistent with these two figures, a far higher number of FGS staff responded positively to the statement that 'children with autism should be taught alongside their typically developing peers: 85% at FGS ticked 'strongly agree' or 'agree' and 33% did so at ABC. However, where the responses between the two settings coincided closely was in response to the statement: 'I would like the opportunity to develop my skills and knowledge for working with children on the autism spectrum': 91.3% at ABC and 95.6% at FGS ticked 'strongly agree' or 'agree'.

The comparison of results between the two settings was skewed by the fact that 5 of the respondents at ABC were therapists rather than all teachers as at FGS. It made good sense to involve them in the survey, even though they were not teachers as they were some of the staff involved in running the autism unit. Also, it should be



said, they perceived their role as an educational one as well as therapeutic (PR1). The therapists were consistently much higher than the teachers in their scores for experience of autism, training and knowledge related to autism and in their support for the idea of inclusion with typically developing peers for children with autism.

**7.6 Working with staff at Amira Basma Centre**

The two settings for my case study, ABC and FGS, were different in many ways and this story from ABC (Table 41) illustrates that. Before going on to write about the involvement of ABC in the research I discuss some differences between the two settings and the value and implications of this for my research.

<p>A story from Amira Basma Centre</p> <p>Samar’s parents always knew that something was different with their daughter. As an infant, Samar was very irritable, especially at bed time. Her physical development was normal, yet at the age of 9 months, her mother noticed that Samar didn’t sit, had no eye contact, didn’t want to join in with activities, play with toys or play with other children. Instead, she watched TV all the time and flapped her hands constantly.</p> <p>At 18 months, Samar spoke only a few words. She used to walk on tip-toe and she had eating problems. She didn’t interact with people, she used her sister to get her things, and communicated by crying and screaming.</p> <p>Samar came to Amira Basma Centre when she was 3 years old and was diagnosed with autism. She needed assistance in all daily living activities such as eating, going to the bathroom, and with personal hygiene, and had problems with her fine motor skills.</p> <p>Samar joined the autism class, where she received occupational therapy, speech therapy, psychotherapy, hydrotherapy, and sensory room sessions, using DIR method and we implemented AAC (Augmentative and Alternative Communication) and a sensory integration approach.</p> <p>After one year of therapy and with the active role of her parents, Samar is partly integrated in the kindergarten of the Amira Basma Inclusive School. She now knows the concepts of sharing and waiting for her turn; she uses the bathroom on her own and has excellent personal hygiene; and she speaks in sentences and although she omits some words she can make herself understood.</p> <p>With on-going treatment, it’s expected that in one year’s time, Samar will be fully integrated in the Inclusive School, coping with her autism and enjoying her childhood.</p> <p>Speech and Language Therapist, Amira Basma Centre</p>
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Table 41: Story from Amira Basma Centre

Whereas FGS is a school and primarily interested in teaching and learning, ABC

started life as a medical centre and has a strong reputation for medical knowledge and practice; it has branched out to include education in response to needs of the community. This is pertinent because in thinking about autism there is a convergence between the world of education and the world of medicine and there is mutual benefit to be derived from collaboration between the two. The lovely story above (Table 41) is about a little girl whose progress I witnessed and it gives cause for celebration. However, 'therapy', used several times in the story, is probably not a word that teachers would use to describe their work. Therapy, you could say, is about healing or putting right a fault whereas education, the teacher might say, is about the active pursuit of knowledge, understanding and skills. Was Samar, the little girl in the story, being healed or was she being educated? There is a difference of position here that goes to the heart of thinking about the needs of children with autism: do they need fixing or do they need educating? I characterised the medical model as one where the child with autism is seen as defective and in need of mending whereas the 'social model' sees the child as legitimately different so that education must be adapted to their needs, rather than trying to adapt the child to fit in with the needs of the school or society. Staff in the autism unit at ABC have embarked on this journey of understanding the difference between education and treatment. Despite the medical language, the little girl in the story was being educated in the sense that she was learning to be a part of her community. As explained by an occupational therapist, they refer to their work as 'rehabilitation' because that gets them the funding but 'we work [to give] education' (PR1). Teachers and therapists have knowledge and skills to share in thinking about the needs of children with autism. The acronyms and therapies listed in Samar's story may sound like alien territory to educators, but there

is common ground. For instance AAC, mentioned in the story about Samar, can be a specialised field but also includes the visual approaches used by the teachers at FGS (p.228); and DIR has similarities to the kind of holistic and individualised approach to child development used by the FGS teachers. There is an overlap between education and therapy and each can learn from the other. The pioneering work of the Centre and the open-minded enthusiasm of the participants have contributed much to the research project. An interesting development has been that the Centre now wants to develop inclusive practices so that the children from the autism unit are enabled to move into the kindergarten and then the school.

ABC's participation in the research began in November 2012, eighteen months after I had begun to work with FGS, so there was not time left to carry out the same kind of cyclical process of action planning and review as planned in my research design, yet the work we did together, the things I learnt and the observations I made contributed a richness to my study. As with FGS, there was an introductory workshop for the whole staff to introduce my research and invite participation. Fifty-five members of staff attended, plus two key members of staff from FGS. The presence of the FGS staff began the logistically difficult process of getting the two settings to work together which was a part of my research design. The FGS staff gave first-hand accounts of their school's involvement in the research. Dr Karen Guldborg, the supervisor for my research, was with me and she introduced training materials that she had helped to develop for the Autism Education Trust. In the UK these materials had 'received overwhelmingly positive feedback from participants' (AET, 2013) and impressive results (ibid), so it was interesting to see how well they would travel across cultures.

There had not been the opportunity to translate or adapt the materials for this particular group. My field notes (Table 42) record my observations.

Extract from field notes (11/12)
... a large, talkative group (55 plus 2 from FGS) sat in a cluttered room with little room for movement. There was a lively interest and lots of verbal participation, with people talking amongst themselves and responding volubly to Karen's input. Could the AET materials offer a model for something that could be developed in Palestine? Some participants seemed to need a more basic content level – 3 people said this to me afterwards. For instance they may have needed a better understanding of the breadth of the spectrum and they seemed to struggle with the notion of autism as a transactional condition. The visual materials would need to be in Arabic, of course, but the content and choice of graphics would also need to be culturally appropriate. I wonder whether an even more interactive learning experience would be more suitable as they seemed keen to join in. The AET materials have been so successful in the UK and one factor in this is probably that they were developed collaboration with a broad range of people with an involvement in the autism world, including autistic people. I believe something like that collaborative approach would be needed here to make it successful.

Table 42: Extract from field notes (11/12)

These observations were pertinent to my main research question about developing inclusive education for autism in Palestine. Could the success of the AET materials and the national programme of training in the UK be replicated for Palestine? My field notes point to a need for cultural and linguistic appropriateness as well as a need to pitch the materials at the right level. This ‘trial’ of the AET materials also prompted thoughts about cultural aspects of preferred learning styles. These issues are further discussed in Chapter 9.

I invited workshop participants to follow-up focus group meeting a few days later and 14 people, comprising teachers and therapists, gave up a Sunday morning to attend and an exploratory discussion generated ideas for action. I would only have one

further field trip to Palestine after this and so the options were more limited than with FGS. A subsequent questionnaire (CD:H8) was analysed (CD:H7) to ascertain what group members would like to do in the time available. Further ideas emerged in a skype meeting, and we agreed on the following:

- A shared workshop with FGS.
- A practical, activity-based workshop on inclusion for kindergarten staff to prepare them for receiving children with autism.
- Myself to accompany the outreach staff to observe their work with a centre in Tulkarem in the WB.
- Members to be invited to join the Wiki.

Members of the focus group had identified a need to develop inclusive practices within the kindergarten at ABC so that children from the autism unit could have the possibility of progression into a mainstream environment. With this in mind, a workshop during my next visit in April 2013 considered approaches to support inclusion and transition from the autism unit to the kindergarten. It was a participatory and practical workshop, lasting 4½ hours (CD:H15). Key staff from the autism unit worked with me to plan and run the workshop so that we could match the content to the needs and this was useful as they could offer examples of their work in the autism unit. 92% (all but one) of participants found the workshop ‘useful’ or ‘very useful’. The emphasis was on practical, affordable approaches, the need for understanding both autism and the individual child, strategies to support and develop communication, transitions and environmental factors, and this is reflected in the list of resources I sent or gave staff at ABC in response to specific requests (Table 43). Participants were very receptive to participatory learning with a practical focus drawing on examples from their own experience.

List of resources requested by staff at ABC
<ul style="list-style-type: none"> <li>• Inclusion Development Programme – Early Years</li> <li>• Checklist to profile the difficulties, strengths and interests of children with autism</li> <li>• Written guidance for including children with autism in mainstream</li> <li>• Video / pictures to illustrate good practice in preparing the environment</li> <li>• Powerpoint slides for peer awareness (used in workshop)</li> <li>• Communication – key strategies</li> <li>• Visual supports –examples</li> <li>• Differences in perception – video used during workshop</li> <li>• Pupil passports (translated into Arabic)</li> <li>• Transition booklet example</li> <li>• Strategies for working with young children (Arabic)</li> <li>• Sensory profile in (Arabic)</li> <li>• Autism and the Ways You Can Help (Arabic) (NAS)</li> <li>• Comic Strip Conversations information</li> <li>• A Guide for Teachers (Autism Education Trust)</li> <li>• What Makes an Effective Practitioner (Peeters and Jordan 2010)</li> <li>• Adult style to encourage communication (Based on the work of Kossyvaki (2011)</li> <li>• Primary Teacher's Toolbox for Including Children with Social Communication Difficulties (including Autism Spectrum Disorders and Asperger Syndrome) (Brown et al., 2006)</li> <li>• Presentation slides from the workshop for kindergarten staff.</li> </ul>

Table 43: Resources requested by ABC (and supplied)

## 7.7 Discussion

It is useful to identify the factors that enabled staff to work successfully with children with autism. The autism unit has trained staff and provides well-thought-out early years provision in a specialist setting for pre-school children with autism. There is a multi-disciplinary approach and a strong ethos of working with parents to support the child. Early intervention is seen as vitally important in providing a sound basis to enable children with autism to benefit from education. The training in Nazareth and in Sweden before the opening of the autism unit provided staff with skills and understanding. Staff consider the child's strengths and interests rather than focussing solely on difficulties and they assess each child's individual needs. There is a readiness to learn and develop, as evidenced by the growing interest in developing

inclusive approaches to enable children in the autism unit to progress into the Kindergarten (Field notes 4/13). Staff gave careful consideration to the most appropriate approaches for their children. For example, although introduced to ABA in Sweden, they decided against this approach, finding it too rigid and 'robotic' (Interview PR1). They chose instead a more eclectic approach towards meeting the needs of autistic children.

Below, I summarise and bring together these success factors with those already described from FGS and ABC, and I relate them to the findings from the wider picture of the contextual enquiry and from the literature review (Table 45, p.246).

### **7.8 Bringing together staff from FGS and ABC**

The literature proposes a need for Palestinian teachers to have opportunities to share knowledge and practice in order to promote teacher empowerment and professional development (Wahbeh, 2011). Steps were taken to try to do this during this study. Firstly, the initial staff workshop at ABC was also attended by two teachers from FGS. Secondly, exchange visits were planned between the two settings, to explore practice in different contexts. It is not easy for busy teachers to be released for visits, but in Palestine there is the added complication of checkpoints and travel restrictions. Nevertheless a group of six FGS teachers obtained travel permits for the journey to ABC in East Jerusalem. Thirdly, staff from the two settings attended a 5 hour workshop (CD:H15) hosted in Ramallah by Qattan Foundation. It was the first time they had come together (apart from the exchange visit mentioned above). I originally proposed that the participants should take a lead in describing and discussing their practice in relation to working with children with autism, so that we could share ideas. However, there was resistance to this idea. Many participants

preferred not to do this and wished me to give the workshop. I complied, but I also built in opportunities for them to share examples of their work. As well as providing data about their developing practice, this tried out a collaboration between two groups of people with a shared interest. Their reluctance to take a lead role in talking about their work is worth thinking about. Maybe they lacked confidence in their work or they lacked confidence in their ability to talk about their work to a new audience. Whatever the reason, this affected my role as an interpretative researcher, described in Chapter Five. My field notes (Table 44) capture something of this quandary.

Extract from field notes (FN 4/12)
I am feeling unsettled about my role. The teachers want me to set targets for them and to tell them what to do. Although I set out to work with them as participants or colleagues working towards a shared goal, they seem to see me as the 'expert' from outside coming to tell them what to do. What is my role within the research? I seem to be a 'consultant' or 'mentor' but how does that sit with an interpretative approach? It puts me in a more powerful agenda-setting role which is contrary to an interpretative approach? And yet I want to respond to their requests for me to share my knowledge and I don't want to undermine their confidence in me as someone with something useful to bring to their busy lives. There are challenges in having the dual role of both 'consultant' and researcher and I often feel as though an authoritative 'teacher' role is what participants want and expect from me. Their own education within Palestine's didactic pedagogy may have led them to expect a traditional relationship between us of passive learner and authoritative teacher. Although we seem to have built a lovely friendly and warm way of relating, there seems to be an uncomfortable and unresolvable tension here in that my researcher role is not wholly clear to all of the participants. The language and cultural differences between us are a barrier here.

Table 44. Extract from field notes (4/12)

**7.9 Commentary on the findings from the whole case study**

Both settings had some staff (teachers and practitioners) with an understanding of autism and some awareness of educational approaches to support inclusion of children with autism. In both settings there was exemplary good practice on which to build. They had in common a strong ethos of working with parents to support the



child, a readiness to consider the importance of the child's strengths and interests rather than focussing solely on difficulties, a recognition of the value of observation and assessment in planning how best to support the child, and an eclectic approach and consideration of environmental issues in addressing the needs of children with autism. However, the two settings were very different and each had different expertise to offer. At ABC, as well as the important focus on very young children, there was also a model of working across professional disciplines to support the child, with teachers, speech and language therapists and occupational therapists working together in a specialist environment. In addition they had recognised the need to plan for transitions into a mainstream environment for children from the autism unit. As well as this, they had identified a need to share their knowledge and experience with others in the West Bank who could benefit from it and they had embarked on outreach work. FGS had developed different strengths as the needs were different. All children were in a mainstream environment and staff sought to put in place the strategies to support that, showing flexibility, a readiness to use visual strategies, an ability to build on pupils' interests, to teach about social situations and feelings, as well as promoting peer interaction. FGS also had a strong learning support department, a commitment to the rights of children with additional needs to be included alongside their peers so that their team of learning support teachers worked alongside teaching staff to support inclusion. Another feature of FGS was that they are interested in thinking about teaching and learning and developing progressive approaches that are uncommon in Palestine.

The majority of staff in both settings wished to learn more about autism practice and were open to new ideas. A final questionnaire found that 85% of respondents at the

two settings wanted to learn more about supporting children with autism. However, findings from the case study showed, as in the other data sets, a lack of opportunity for teachers and practitioners to learn about autism practice and a lack of culturally specific resources and information in Arabic. There was a lack of specialists for schools to call upon for advice in addressing the needs of pupils with autism and this was also evident in data sets one and two.

The inclusion of children with autism had developed differently in each setting. FGS held a model of inclusion based on flexible approaches and adapting teaching styles to suit the needs of the individual. At ABC the embedded model of inclusion within the main school was different from this and could more accurately be described as integration. The support assistant, rather than the teacher was seen as holding responsibility for the child's learning (Interview T5). However, the period of my study saw growing interest at ABC in developing inclusive approaches and staff are currently working together to develop a model of inclusion which is about meeting individual needs of autistic children alongside their typically-developing peers within the mainstream kindergarten. Inclusion for children with autism became a more prominent issue for staff during the time span of this research (PR1) and developments provide a new model for thinking about inclusion. 70% of participants in the two settings expressed readiness to support other schools and centres wanting to develop autism practice.

I now consider whether these findings offer broader insights into what might be applicable in Palestine as a whole. I acknowledge a need to be cautious in any attempt to extrapolate from the particular in order to talk about the general, especially in this instance as neither of the two settings is a government school. I look at the

actions and values in the two settings that enabled them to work successfully with children with autism and, with reference to the contextual enquiry and my reading, consider whether these conditions might be possible to replicate more widely. Table 45 identifies factors that enabled the two settings in the case study to include children with autism successfully. The right hand column considers the evidence from the research to ask whether these conditions prevail in Palestine as a whole.

<b>Factors contributing to successful outcomes for pupils with autism</b>	<b>Can these conditions be met in government schools in the Palestine?</b>
<b>Support teachers</b>  There are support teachers / practitioners who work in partnership with teachers in the classroom to support pupils with additional needs.	At present there are no support teachers in government schools (Farrell, 2007).
<b>Student –centred approach</b>  Progress towards and commitment to flexible student-centred approaches with the IB programme and LBD initiatives at FGS.	Rigid, didactic teacher-centred approaches (Wahbeh, 2011; Interview T1; NAD, 2010).  Most teaching is not conducive to learning for SEN students (Karlsson, 2004).
<b>Addressing individual needs (SEN)</b>  Both settings think about the individual needs of children and have used pupils profiling to guide their work.	Teachers do not address individual needs (Al-Ramahi & Davies, 2002).  High speed question and answer sessions / no thinking time / children read aloud in chorus and encouraged to 'scream' Karlsson, 2004 (Note: children with autism often i) have sensory sensitivities and ii) process language slowly.
<b>Autism-specific strategies</b>  Staff use an eclectic range of specific approaches to support pupils with autism.	Lack of expertise in Centres (Zayed et al., 2012)  But there are some skills and knowledge: Friends of Autistic Children Society uses TEACCH and PECS (MoEHE focus group 2).  Teachers in government schools do not have the skills (Interviews M1; M2).
<b>Training</b>  Training and awareness about autism has been initiated both by Head of Learning Support and her successor at FGS, as well as the development that has taken place through this research.  At ABC, staff took lengthy training before opening the autism unit.	There is a lack of training related to SEN in general (Opdal, 2001). Teachers have not had the opportunity to learn about teaching children with autism (Interviews M1, M2, T1).
<b>Attitudes towards children with additional needs</b>  There is a wish to learn about supporting children with autism in schools (evidence from	'Teachers (in Palestine) seem to have become more mature and ready to acquire information about disabilities' (Lifshitz, 2004:185). 90% teachers want change to meet needs of children

questionnaires).	with SEN.
<b>Inclusion</b>  There is an understanding of inclusion and implementation of inclusive policy at FGS.  ABC is developing inclusion to enable children from the autism unit to progress to kindergarten.	MoEHE has a policy of inclusion and is signed up to the EFA initiative. SEN students are integrated socially (Karlsson, 2004); there is a lack of understanding of inclusion (Farrell, 2007); 60% of teachers in Opdal's (2001) study said children with SEN should attend mainstream. Whereas Lifshitz (2004) found that Palestinian teachers were less inclusive than their Israeli counterparts.
<b>Leadership</b>  In both FGS and ABC there are knowledgeable leaders who can provide guidance.	SEN coordinators are overloaded, lack training and are not always identified.  Inclusive Education Counsellors lack training in autism (p.186).
<b>Parents</b>  The parents are strong advocates for the rights of their children to benefit from their education.	Increasingly, parents are demanding good education for their children with additional needs (Interview M2). However, many parents are reluctant to assert their children's rights (Dababnah and Parish, 2013).
<b>Working with parents</b>  Both settings liaise closely with parents and see this as very important in their practice.	Most centres work with parents and believe it is important to do so (Zayed et al., 2012).  I have no data on this relating to schools in Palestine.
<b>Sharing of information between colleagues in different settings.</b>  At ABC there is a strong ethos of working to support centres in the West Bank, sharing knowledge and skills and working in collaboration.  FGS has expressed willingness to share their growing expertise.	Centralised control in Palestinian schools works against opportunities for teachers to share ideas within communities of practice (Wahbeh, 2011).  Shortage of outreach programmes in WB (Zayed et al., 2012).
<b>Multi-disciplinary working</b>  Teams work together to support children at ABC.	MoEHE has developed 2 multi-disciplinary Resource Centres to support children in schools.
<b>Early intervention</b>  Pre-school children aged 3 can start at ABC autism unit.	No data.
<b>Belief in the importance of education</b>	There is a strong commitment to the importance of education (Nicolai, 2007; Gumpel & Awartani, 2003).

Table 45: Factors contributing to successful outcomes for children with autism

There is a disjuncture between my research findings and the research literature relating to Palestine in that there are pockets of good autism practice in Palestine, shown here in table 45 and elsewhere in the contextual enquiry, that are not

evidenced in the research literature. The discrepancy between my findings and the literature may be because autism is a new topic in Palestine. The research found evidence, albeit limited, of recent pioneering developments in relation to autism. As one interviewee said: 'there is a new awareness now of autism in the media. It is now talked about' (T1). I believe my research shows that there is a will and a possibility to develop good practice in Palestine for children with autism, as well as a compelling need to do so.

Table 45 listed factors that contributed to the successful inclusion of children with autism at FGS and ABC. A closer look shows that the teachers and practitioners who took these initiatives firstly recognized a need to develop inclusive approaches (FGS), or a need to make provision for young children with autism (ABC). Then, equipped with some knowledge and skills they had the backing, resources and conditions that enabled them to bring about change and open the doors to children with different needs. They had the resources, possibly because they were not dependent on government funding. Successful change in the case study settings depended on several key components:

- seeing the need
- having the will
- having the necessary support
- taking collaborative action
- dynamic leadership

The case study demonstrated a potential for shared learning of new knowledge and the eliciting of tacit knowledge organically within the practice and culture where it was wanted, pointing to the potential value of a CoP approach. The tight social bonds

within the case study groups, the shared area of concern and the enthusiasm for learning created embryonic CoPs. My previous discussion of CoPs (p.78) refers to the need for 'social artists' or dynamic leaders at their core (Wenger et al., 2002). My case study included people such as this: pioneering, committed people whose involvement gave cohesion and confidence to the group, so that participants, more than simply gaining new knowledge as they might on a training course, identified with and were empowered by being part of the group. The effectiveness of the negotiated approach to the development of practice in the case study adds weight to the proposal in my thesis for CoPs as a means of developing practice and harnessing knowledge on a wider scale. The expressed willingness of the participants to share their learning with others, and indeed the current outreach work undertaken by ABC staff, indicated a climate conducive to the peer-to-peer knowledge sharing of CoPs. The experience of the shared workshop when the two settings came together (p.242) suggested the need for careful negotiated planning for the CoP approach to work. Convened with care (Guldborg, in press), CoP offers the possibility of a knowledge-sharing community across a broad landscape of practice within Palestine and beyond, bringing together teachers, practitioners, researchers, policy makers, communities and, importantly, people with autism.

Before offering conclusions and recommendations in the final section, my penultimate chapter looks at the findings from the study day that took place after the completion of the case study and contextual enquiry.

## **CHAPTER 8: THE STUDY DAY (Data set 4)**

This section of my thesis forms a bridge between primary research findings and the meta-analysis in the final chapter. After completion of my data collection, QCERD hosted a Study Day in February 2014 in Ramallah where I presented my research findings. For this I wrote an interim report of 38,000 words (Ashbee, 2013) that was translated into Arabic and distributed in advance. As well as giving my feedback on the research, the day brought together participants for discussion of the issues it raised. Attendees (CD:J3) included teachers, parents, practitioners, education ministry staff, therapists, medical professionals and academics, all with an interest in autism and education, to explore issues raised in the research. A limit of 60 places would allow effective sharing of ideas although the final number was 68. The event attracted media interest including two television crews and a newspaper reporter. The programme (CD:J2) included a presentation of my research followed by discussions, supported by a bilingual translator whom I prepared in advance for the role. I used a Powerpoint, which was highly visual and in both English and Arabic. As well as presenting findings and recommendations, this was an opportunity to hear the opinions of this diverse group of people.

For the afternoon session participants divided into five discussion groups, randomly allocated in advance with group leaders who had been briefed. Groups divided time equally between three questions given on a handout (Figure 41). An hour was allocated for group discussions and a high level of animated involvement was observed. This was followed by feedback from each of the groups with main points summarised on flipcharts. A translated transcription of the flipcharts is shown in

Appendix 14. Discussions, feedback and open discussion were video recorded by QCERD. Although I have this on a data storage device, it was not possible for it all to be translated. My translator / assistant's contract had ended by this stage and the meticulous support that QCERD provided for this event did not extend to the time-consuming chore of transcribing and translating several hours of video recording. So I only had partial access to what was said. My field notes record that people spoke passionately and at length about the issues and that I was in the presence of energetic fighters and campaigners for autism.

Study Day – questions for group discussions
<p><b>1. Priorities</b> What are the priorities for Palestine in planning for the education of children with autism?</p> <p><b>2. Collaboration</b> The research recommends that there should be collaboration between people from different backgrounds (eg. education professionals, community providers, health professionals, ministry personnel and parents) to work together to develop a strategy for autism for the West Bank and East Jerusalem. What is feasible in Palestine?</p> <p><b>3. Inclusion</b> The Ministry of Education has a policy of inclusion. What are the next steps in promoting inclusion for children with autism?</p>

Figure 41: Study Day Questions for Group Discussions

Groups gave verbal feedback in Arabic, translated for me *in situ*. My field notes of key points supplemented the translated flipchart notes when I analysed the group discussions. For each of the three questions I thematically grouped the comments. Analysis of the study day brought into focus for me the profound complexity of my main research question and that there are no easy answers; at every turn there are issues within issues and a need for further questions. I look in turn at each of the three questions I gave to the participants.



## 8.1 Discussion 1: Priorities

### What are the priorities for Palestine in planning for the education of children with autism?

Analysis (CD:J6) placed responses into seven thematic groups (Table 46)

What are the priorities for Palestine in planning for the education of children with autism?
<ul style="list-style-type: none"><li>• Diagnosis and identification of needs</li><li>• Education / provision for children with autism</li><li>• Training</li><li>• Social awareness</li><li>• National strategy</li><li>• Data</li><li>• Parents</li></ul>

Table 46: Study Day, Q1 - Themes

A tally of comments in each group (Figure 41) gives a rough indication of priorities, although participants had not been asked to rank their priorities and it is possible that data from the group feedback did not represent the priorities of the groups. Also, having just listened to my presentation may have coloured participants' sense of what was important. I discuss the issues raised within each of the seven themes.

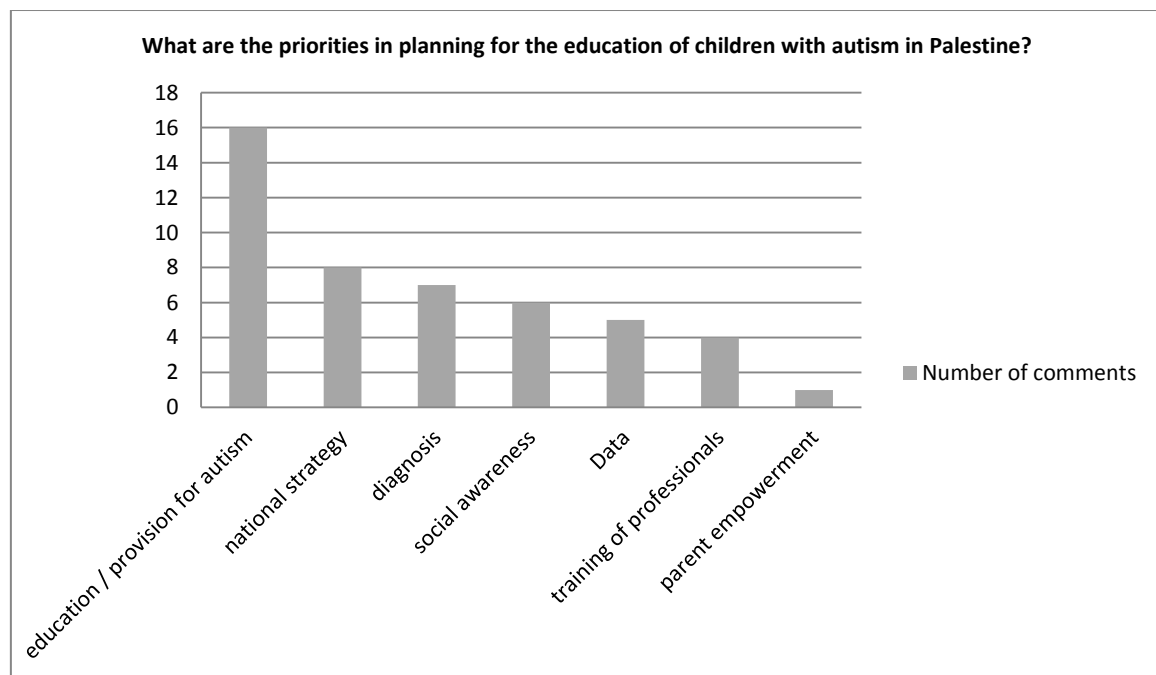


Figure 42: Seven thematic groupings – tally of comments (Question 1)

### **Theme 1: Education / provision for children with autism**

Issues raised (Table 47) reflected the participants' sense of the complexity of making provision for the education of children with autism, and an awareness that there were no 'magic bullets' as the issues raised are not simple. For example, three comments related to the need to provide an appropriate environment for children with autism, a complex but important issue discussed above in Chapter 4. Two comments highlighted the issue of early intervention, again a key issue in the literature. Two comments related to the need for adaptation to the syllabus or the curriculum, again not straightforward. Other comments also embodied complex issues: the need for one-to-one support; the need for agreed strategies; the need to reduce the load on teachers; the need for acceptance of children with differences; and the need for changes in education as a whole. One group wanted children with autism to have access to therapy. It was interesting that, in this discussion, the issue of inclusion was not raised as a priority whereas one group wanted, as a priority, 'special education for children unable to be included' and another group prioritised the establishment of 'organised centres and institutions', suggesting a desire for 'special' provision and 'institutions' outside the mainstream school environment.

<b>Theme 1: Education and provision for autism</b>
<ul style="list-style-type: none"><li>• Provide for early years education (3-6) and school education.</li></ul>
<ul style="list-style-type: none"><li>• Early intervention leading to suitable plans</li></ul>
<ul style="list-style-type: none"><li>• Provide a supporting environment</li></ul>
<ul style="list-style-type: none"><li>• Provide individual assistance</li></ul>
<ul style="list-style-type: none"><li>• Provide therapy sessions for support throughout school years</li></ul>
<ul style="list-style-type: none"><li>• Special education for kids who are not able to be included</li></ul>

• Adapt the syllabus to suit the students with special needs
• Establish organized centres and institutions
• Prepare a convenient physical environment for children with autism
• Agree on strategies to educate and rehabilitate children with autism
• Renovate buildings
• Reduce load on teachers (field notes)
• Adapt the curriculum in schools and in universities (field notes)
• Develop education in general (field notes)
• Schools should accept difference (field notes)

Table 47: Comments about education

Findings resonate with findings from the contextual enquiry which identified need for educational provision for autistic children of all ages, including early years, within an enabling environment with appropriate levels of support, an appropriate curriculum and suitable teaching styles and strategies. Here, as in previous data sets, there was evidence of a perceived need to embrace difference, a need to develop pedagogy beyond the prevailing traditional teacher-centred approaches and a need to adopt more flexible student-centred styles, as well as a perceived need for ‘therapy’.

## **Theme 2: National Strategies.**

Comments here (Table 48) came almost entirely from one group and reflected a need to think strategically, and were consistent with findings from my reading and other research findings. The need for collaboration, seen in two of these comments, is a recurring theme in my study and one that I dwelt on towards the end of the previous chapter (p.248). The fact that collaboration does not emerge more strongly as a priority here, in the analysis of question one, could perhaps be because

participants looked ahead and saw that the second discussion question related to collaboration.

<b>Theme 2: National strategies</b>
<ul style="list-style-type: none"> <li>• Issue a written, clear and binding ministry policy</li> </ul>
<ul style="list-style-type: none"> <li>• Form a national committee that includes all segments of society to follow up on policies and plans</li> </ul>
<ul style="list-style-type: none"> <li>• Establish organized centres and institutions</li> </ul>
<ul style="list-style-type: none"> <li>• Develop a national comprehensive plan (government, civil institutions)</li> </ul>
<ul style="list-style-type: none"> <li>• Set goals and indicators to evaluate the plan and measure its success</li> </ul>
<ul style="list-style-type: none"> <li>• Establish clear policies (FN)</li> </ul>
<ul style="list-style-type: none"> <li>• Develop a strategy for childhood and adulthood (FN)</li> </ul>
<ul style="list-style-type: none"> <li>• Ministries need to work together (FN)</li> </ul>

Table 48: Comments about strategy

### **Theme 3: Diagnosis**

Diagnosis, frequently mentioned elsewhere in the data, received a significant number of comments (Table 49). Priorities included a need for ‘reliable diagnosis’ and ‘early diagnosis’ by ‘professional teams’ equipped with ‘diagnostic materials’. One group prioritised a need for ‘a national diagnosis centre and a training centre’. These are issues that I carry forward to my final chapter.

<b>Theme 3: Diagnosis</b>
<ul style="list-style-type: none"> <li>• Early discovery (identification)</li> </ul>

• Reliable diagnosis
• Reliable diagnosis and professional teams for diagnosis
• Opening a national diagnosis centre and a training centre
• Early and correct diagnosis
• Obtain diagnostic materials (FN)
• Create a framework to assess a child's needs (FN)

Table 49: Comments about diagnosis

#### Theme 4: Social Awareness

The need for social acceptance, recognition of children's rights and for the wider community to have awareness and understanding of autism (Table 50) emerged as a theme. One group said it was not only about autism: 'there needs to be social acceptance of difference'. Two groups specified the need to think in terms of 'children's rights'. The issue of 'including children with autism in the health insurance', indicative of seeing autism as a medical issue, had not previously been raised in my research. In the UK it is unusual to think in terms of health insurance for autism, whereas in the US, where ABA is favoured, parents often seek out this form of treatment, amounting to perhaps 30 hours per week, costing up to \$40,000 per year (The Guardian, 2014), and leading to legal battles with insurance companies.

<b>Theme 4: Social awareness</b>
• Provide a suitable and welcoming environment for social inclusion (eg. through community awareness campaigns)
• Raise awareness about autism in society
• Not only about autism. There needs to be social acceptance of difference (FN)
• Increase awareness about children's rights generally and children with autism specifically

<ul style="list-style-type: none"> <li>• Work on changing the attitudes toward children's rights</li> </ul>
<ul style="list-style-type: none"> <li>• Including children with autism in the health insurance</li> </ul>

Table 50: Comments about social awareness

### Theme 5: Information

I grouped some priorities together under 'Information'. Two groups called for 'research to provide statistics' and a 'database'; another called for 'research for assessment of needs'; another for 'a unified database that is easy to access and that includes all the available data about autism in Palestine'.

Theme 5: Information
<ul style="list-style-type: none"> <li>• Carry out research and provide statistics</li> </ul>
<ul style="list-style-type: none"> <li>• Build a database and provide statistics</li> </ul>
<ul style="list-style-type: none"> <li>• Conduct research and an assessment of needs</li> </ul>
<ul style="list-style-type: none"> <li>• Create a unified database that is easy to access and that includes all the available data about autism in Palestine</li> </ul>

Table 51: Comments about data / information

### Theme 6: Training of professionals

Within this theme, priorities included a perceived need to 'develop the potential of therapists and educators', 'build human capacities (train teachers, doctors, counsellors)' and 'train practitioners'. One group wished to 'open a national training centre' and another to 'introduce programs and information sources that are available for everyone'.

I was surprised that this group held only five comments, as the need for training was the biggest area of recommendations in my report and in my presentation.

Theme 6: Training of professionals
<ul style="list-style-type: none"> <li>• Develop potential of therapists and educators</li> </ul>
<ul style="list-style-type: none"> <li>• Build human capacities (train teachers, doctors, counsellors)</li> </ul>
<ul style="list-style-type: none"> <li>• Train practitioners</li> </ul>
<ul style="list-style-type: none"> <li>• Open a national [diagnosis centre and a] training centre</li> </ul>
<ul style="list-style-type: none"> <li>• Introduce complementary programs and information sources that are available for everyone</li> </ul>

Table 52: Comments about training

## Theme 7 Parents

A single comment related to parents. This was surprising as there was a sizeable number of parents present. The comment was simply to ‘empower parents’ and, again as in data set 2 (p.200), suggested a view of parents as lone warriors in support of their children rather than collaborative partners.

Theme 7: Parents
<ul style="list-style-type: none"> <li>• Empower parents</li> </ul>

Table 53 Comments about parents

## 8.2 Discussion 2: Collaboration

**The research recommends that there should be collaboration between people from different backgrounds (eg. education professionals, community providers, health professionals, ministry personnel and parents) to work together to develop a strategy for autism for the West Bank and East Jerusalem. What is feasible in Palestine?**

This was an important question for participants to consider. My reading had shown that good autism practice depended on collaboration between the various stakeholders (p.63); my reading on CoPs had persuaded me of the value of

collaborative learning (p.78); my reading about teacher development in Palestine had shown that teachers lacked opportunities to share knowledge and expertise (Khaldi & Wahbeh, 2002). Findings also suggested that although there were parents and professionals working for autistic children, this was in isolation from each other and without the opportunity to share learning. A summary of the groups' comments about what forms of collaboration were feasible is given below in Table 54.

	<b>Q2. Collaboration. What is feasible in Palestine?</b>
1	Collaboration between autism professionals and practitioners in the field
2	Form a national committee from different institutions and schools
3	Set clear rules and regulations by governmental institutions to control the work of the institutions working with autism
4	Form a committee for cooperation, identifying responsibilities, goals, vision and message
5	Form pressure groups, local committees or coalitions that work and cooperate with the different parties and coordinate them
6	Periodical meetings between the different parties through workshops and conferences.
7	Collaboration between doctors, institutions and professionals under ministerial supervision
8	Networking between parents
9	Found a body as an umbrella for the different institutions and parties working with autism
10	Forming pressure groups to advocate the rights of people with autism
11	Need for collaboration (FN)
12	Work together to produce a guide for everyone (FN)
13	Come together to make a national plan for autism (FN)
14	Provide a clear data base for professionals
15	Develop a web forum for all the autism centres and institutions
16	Use the available resources
17	Exchange of expertise between the different parties using media or social networks



18	Create electronic web pages
19	Start a web forum for networking

Table 54: Responses to question 2

Responses, although general, are positive in wanting collaboration to develop a strategy for autism in Palestine. Further analysis of responses shows six that simply support collaboration (Responses 1, 2, 5, 6, 9, 11). One group specifies 'networking between parents' (Response 8) although, interestingly, this is not suggested to be in collaboration with other groups and none of the other responses specified 'parents'. This seems to correlate with the responses to Question one where only one group (a different group) prioritised the importance of parents.

Two groups (Responses 4 and 6) suggested the form that multi-agency collaboration should take; and one group proposed who should take responsibility of leadership (Response 7) with the words 'ministerial supervision', without specifying which ministry. One response (16) highlighted the need to build on existing assets and strengths. Another response (10) felt the focus should be on children's rights and the formation of a pressure group. Two comments (12 and 13) suggested that an outcome from collaboration should be the introduction of national standards for autism, and one comment (3), proposed government 'control'. Five responses (14, 15, 17, 18 and 19) related to the possibility of web-based collaboration, a suggestion that I also made in my report.

One omission, understandable but pertinent, was the absence of any mention of people with autism in the responses about collaboration. Although this would be a surprising omission in a European context where autistic people are in the vanguard

of autism development, it is not surprising in Palestine where, as my findings suggest, people with autism are marginalised.

Although the word 'education' was prominently in the title of the Study Day, data contain only one education-related word (Response 2: 'schools'). Could it be that developing autism practice was not seen to the job of people involved in education? This is a tantalising question. My report and presentation had unwaveringly supported the importance of education for children with autism but it is reasonable to suppose that there is still uncertainty as to what this means for Palestine.

I considered earlier that responses to the questions had possibly been influenced by my preceding presentation. Analysis of the responses does not support the view that participants parroted back ideas from my presentation or report. The importance of education, the importance of parents and the importance of including the voices of people with autism are just three of the issues that I highlighted that are not prominent in the participants' responses.

### **8.3 Discussion 3: Inclusion**

**The Ministry of Education has a policy of inclusion. What are the next steps in promoting inclusion for children with autism?**

Analysis of the 29 responses to this question (Table 55) considered many issues related to promoting inclusion for children with autism. Two comments expressed frustration with lack of progress towards inclusion, pleading 'enact the existing laws' and 'we need more than resolutions: we need to apply them'. Similar comments emphasised a 'need to apply the Education for All policy to autism' and 'link the right of education for children with autism with the overall policy'. One group, flagging up

challenges of inclusion, cautioned that 'application is hard'. Financial implications were commented on by two groups who said, 'financial support is needed' and there was a need to 'allocate budgets'. One group advocated 'support and assistance for the existing institutions'. This chimed with contextual enquiry findings showing lack of government support for centres in the community and reliance on insecure donor funding. Surprisingly, only one group mentioned teacher training although this had emerged as an important issue in both strands of my research and my report discussed this issue at length. There were two calls for 'better identification of autism' and 'early and correct diagnosis'. Several comments pointed to the importance of collaborative approaches, calling for 'networking between the different institutions and centres' and a need 'to enhance the role of local communities as partners in the education process and inclusion'. Three comments pinpointed need for specialist teams: 'a specialised team that follows up on the child's needs'; 'a specialised committee' and 'specialised teams at schools level and at Ministry level'.

Ten responses, the biggest number, commented on the nature of the provision that was needed for promoting inclusion for children with autism. Of these, three focussed on 'environment': 'Focus on changing the environment around children with autism'; 'Provide a suitable environment' and 'Provide an appropriate environment'. Some advocated 'therapy where needed' or more specifically 'music therapy, art therapy, water therapy, speech therapy'. For others, 'assigning teacher assistants' and '1:1 support' was needed. The issue of resources appeared in another comment: 'Provide suitable tools and materials for children with autism'. One participant's comment that 'there is ambiguity about inclusion' correlates to findings of lack of clarity about inclusion in the main body of my findings .

Q3. What are the next steps in promoting inclusion for children with autism?	
1	Regarding the first step, application is hard
2	Enact existing laws
3	Apply the Education for All policy to autism (FN)
4	Need more than resolutions we need to apply them (FN)
5	It is about social inclusion (FN)
6	There is ambiguity about inclusion (FN)
7	Networking [needed] between the different institutions and centres
8	Direct support and assistance for the existing institutions
9	Implement the steps in section one as initial interventions
10	Better identification of autism [is needed]
11	Form a specialized committee
12	Form a specialized team that follows up on the child's needs
13	Teacher training
14	Allocating budgets
15	Set firm and clear policies on how to help children with autism
16	Early and correct diagnosis is needed
17	Comprehensive and continuous follow up
18	Link the right of education for children with autism with the overall policy
19	Urge educational bodies (eg. Ministry of education) to enhance the role of local community as a partner in the education process and inclusion
20	Need for specialized teams at schools level and at Ministry level (FN)
21	Financial support is needed (FN)
22	Provide an appropriate environment
23	Provide 1:1 support
24	Provide therapy where needed
25	Provide suitable tools and materials for children with autism
26	Provide a suitable environment

27	Assigning teacher assistants
28	Provide music therapy, art therapy, water therapy, speech therapy
29	Focus on changing the environment around children with autism

Table 55: Responses to question 3

The day after the Study Day, QCERD called with a message from parents who had attended and wanted to bring their son to me so that I could advise them. It was not possible as I had a full schedule up until my departure, and I am not sure how useful I could have been in any case. This had happened before when word got round that a supposed 'expert' was in the country, supporting evidence elsewhere in the data and the literature (Dababnah & Parish, 2013) of parents desperate for support. The Study Day findings tallied with other research findings: concern about lack of reliable diagnosis; the existence of knowledgeable people who are passionate about autism; the need to develop provision and practice; and the need to move away from traditional approaches to teaching. A notable gap, from a western viewpoint, was omission of the autistic voice when thinking about the need for collaboration (Q2) and when thinking about priorities (Q1); this agreed with findings elsewhere. More surprising was that parents were not highlighted as necessary partners for collaboration (Q2) and support for them was not listed as a priority (Q1). Two significant areas seemed to lack shared clarity. One was the meaning of 'inclusion' for Palestine. The other was the way that autism is conceptualised in relation to education: is it better to include the child in education or to give them therapy? Collaboration to share and harness knowledge and develop practice is the thread that runs through my study, and this final study day reinforced this cornerstone of my thesis.

## **CHAPTER 9: CONCLUSIONS**

### **9.1 Introduction**

I offer the following as a contribution to the development of inclusive education for children on the autism spectrum. The findings may sometimes sound critical but that is not the intention: rather, it is to try to spotlight areas that may be worth considering. The suggestions are offered in the spirit of solidarity, and with admiration for the Palestinian struggle for the inclusion of children with autism that I have found in my study. This chapter draws together findings from my study and presents a summary of my thesis on the opportunities that can be found to develop inclusive education for children with autism in Palestine. I also consider the relevance of this research as well as its limitations and I discuss dissemination of my thesis.

### **9.2 Key findings in relation to the research questions**

The seven subsidiary research questions were an essential feature of the interpretivist research design, enabling me to address the main research question, through the prism of Palestinian experiences and perspectives. The main findings are presented here in relation to each subsidiary question in turn, before moving to the main research question where I draw implications and suggestions stemming from my findings.

#### **9.2.1 How is inclusive education regarded in Palestine?**

Despite widespread support, professionals and policy makers do not have a shared understanding of 'inclusion'. It is not clearly distinguished from integration and is mainly understood in terms of placing a child in a setting rather than adapting the environment to enable the child to participate and thrive. Inclusion is a growing area

of interest and some individuals and organisations, such as QCERD, the Jerusalem Inclusion Project, and the two settings involved in my case study, are developing new approaches to inclusion that are about the process of identifying and understanding needs in order to overcome barriers to participation and social belonging.

### **9.2.2 How is autism understood in Palestine?**

The research found that autism is not well understood in Palestine. The idea that autism is a broad spectrum that includes a wide range of abilities is not well known and autism is mainly seen in terms of deficits so that a medical model predominates and a person with autism is likely to be seen as 'mentally retarded'. Autism is often stigmatised leading to social isolation for autistic people and their families. However, there is a growing interest in autism, attitudes are changing and there is a strong interest in finding out more. Some people have good understanding of autism although they tend to work in isolation from each other.

### **9.2.3 How are children with autism identified, educated and supported?**

There is widespread lack of reliable autism diagnosis in the West Bank although there are regional disparities. There are no statistics to show the incidence of autism in Palestine or how this relates to other regions of the world. Parents and professionals are frustrated by the hidden status of autism and feel that improvements in provision and practice would result from proper identification. Although a few children with autism attend mainstream school it is likely that the vast majority of children with autism do not go to school. Centres in the community that accept children with special needs are funded by fees and charitable donations and are sometimes financially insecure. Autistic children are sometimes identified within

these centres and some centres have recently introduced discrete groups for children with autism, probably those seen as the least challenging. A few centres, similarly funded, specialise in provision for autistic children. Teachers and practitioners have not had training to meet the needs of children with autism and there is an absence of specialists to guide practice. Many children with autism are kept at home with no support for them or their families; some are placed in institutions unable to address their needs. Children with autism are often given medication to treat symptoms and parents sometimes resort to internet 'cures'. Evidence suggested little consistency or coherence of understanding amongst teaching professionals and misconceptions that could significantly affect the support offered to a child with autism. The special needs team at the Ministry of Education wish to do more to address the needs of autistic children.

#### **9.2.4 What are the barriers to progress in inclusive education for children with autism?**

There is little or no access to training in practice related to autism for professionals and for community providers and no access to specialist expertise. Universities in Palestine do not offer in-depth courses in autism<sup>27</sup>. Without an understanding of autism it is difficult to implement practices to enable the inclusion of a child with autism. Also, current traditional teacher-centred approaches to teaching and learning are not conducive to inclusion of children with differing needs. The non-identification of children with autism means that this is a 'hidden' issue.

Palestinians value education highly and hold a belief in inclusion. However, the unstable political situation, social fragmentation brought about by the occupation and

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<sup>27</sup> I learnt of two developments during the research period: The SEN Diploma at Ahliya University that included a section on autism and the more recent introduction of a 'periodical course on autism' at An Najah University.



limited financial resources have restricted opportunities to develop this field. Another limiting factor is that there is no clear understanding of which government departments should take responsibility for autism and there is a perceived lack of clear, shared, co-ordinated Government policies.

#### **9.2.5 What is the experience of families and their relationship to other stakeholders?**

Parents lack support and may experience social rejection of their child with autism. They struggle to find suitable educational placements. Some parents have led the way in trying to build alliances to support each other and value the contact with other parents of autistic children. The Coalition for Autism, the national organisation, folded for lack of finance. In the absence of other support, parents sometimes turn to the internet for help and some look for medical solutions as an answer to the challenge of autism.

The importance of parents as collaborative partners was not always recognised by education professionals, although, in the two settings for my case study and in the centres I visited parental involvement was encouraged. The study found that parents were good observers of their children and their knowledge of their child enabled them to identify strengths as well as difficulties and to find approaches to help them. There was no data to support the idea of collaboration with people with autism, either by listening to the voices of children with autism or by listening to autistic voices.

#### **9.2.6 To what extent are ideas from the UK and elsewhere useful?**

It is difficult to draw conclusive answers here and my responses to this question rely on subjective reflection on the findings. In my opinion, a concept of inclusion that is

about a process of identifying and understanding needs in order to overcome barriers to participation and social belonging, would be useful in enabling Palestine to make a reality of their desire for educational inclusion. The practical outcomes of this for Palestine, where education has a different legacy, schools are run differently and finance is limited, are not immediately clear and the UK's 70% inclusion into mainstream rate for children with autism may not, in the short term, be a realistic goal for Palestine.

There is an international reservoir of knowledge and research about autism practice on which it would be useful to draw. The way that autism is conceptualised is important too and seeing autism as a transactional condition would be helpful. A social model of disability rather than a medical model would be valuable in enabling schools to include children with autism. The AET autism training materials were partially trialled during the research, during staff training at ABC, on the Early Years Diploma<sup>28</sup> course run by QCERD, and selectively during other workshops. They stimulated interest and discussion raising the possibility that this well-researched body of materials could be adapted for Palestine, taking into account cultural expectations and preferences. The collaborative approach to developing the materials was important to their success pointing to the potential value of CoPs, discussed below.

The practices and approaches that the participants and I introduced during the case study, with an emphasis on low cost, both in terms of finance and time, were easily and usefully imported into the Palestinian context. Some of these are listed in Table

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<sup>28</sup> Dr Karen Guldberg used a selection of the AET materials with the Early Years Diploma teachers when she was invited to work with them during her visit to Palestine in November 2012

39 (p.226) and included the use of visual supports, transition planning, Social Stories and pupil observation and profiling, all easily adapted for local needs. However, practice needs to go hand-in-hand with understanding.

#### **9.2.7 What can Palestine contribute to the international discourse on educational inclusion for children with autism?**

There is proactive building of knowledge and understanding about educational inclusion for children with autism in Palestine. This is shown in the stories from the case study (Tables 40, p.230 and 41, p.236) and in the list of favourable factors for autism in the two setting (Table 45, p.246). In addition, Table 23 (p.166) gives examples from the wider context of initiatives and developments in the field of autism. There are undoubtedly other initiatives that were beyond the reach of this research.

I would argue that Palestine not only could, but should contribute to the international discourse as there is much to be learnt from its contribution, both for the enrichment to global perspectives and for the empowerment of Palestinians who have sometimes been pushed into the role of passive recipients of western ideas and handouts. The gap in the literature relating to autism and inclusion in Palestine offers opportunities for studies related to the specific needs of that region, studies that could be significant in the wider Arab world where Palestine's strong record and high regard for the value of education is notable. Palestine could contribute to shared concerns about autism across the region, making connection between international learning and local needs. There is a need for better understanding of autism in disparate cultures, to explore how culture affects perceptions and perhaps also the development and the identification of autism. Opportunities exist to take and adapt

what is culturally appropriate from the global resource bank as well as to contribute new approaches arising from Palestine's unique experience. Palestine can also contribute to the international discourse on inclusion. As Mittler (2003) writes, each country needs to find its own route to inclusion and Palestine's contribution here could broaden global understandings to give a more inclusive perspective on inclusion. Engaging in discourses on educational inclusion for autistic children is potentially beneficial for Palestinian education as a whole. Inclusive education for children with autism is good education and can be a model for thinking about the education of all children (Jordan, 2008). Educational thinkers in Palestine are developing approaches that are less rigidly didactic and so Palestine is well placed to offer a spur towards a more progressive pedagogy that is able to include all children. This would be a valuable international contribution. The Palestinian perspective also has the potential to be instructive in thinking about how to share, develop and harness knowledge and practice in circumstances where geographical fragmentation make this challenging. There are avenues to be explored here about the potential of digital technology for overcoming these challenges and this could be related to thinking about the development of CoPs across international boundaries too. Palestine is situated in a geographical crucible of three of the world's major religions, Islam, Christianity and Judaism, as well as having a vibrant secular population. The implications of this in terms of inclusion, attitudes towards difference, social values and cultural practices in relation to autism have barely been touched on in my study but offer rich ground for research.

### **9.3 Implications**

I now tease out some implications from the findings, as a bridge to the recommendations.

#### **9.3.1 Knowledge, understanding and skills**

The research shows a need for better understanding of autism amongst teachers, practitioners, parents and all who come into contact with children with autism. There is an international body of knowledge and research on which to draw as well as notable progress in this field in Palestine. It is not just a matter of training a few support teachers or practitioners, there is a widespread need for understanding, knowledge and skills.

#### **9.3.2 Reconceptualisation of inclusion**

Research findings agreed with Opdal (2001) and Farrell (2007) that inclusion has support in Palestine but that it is not widely understood. Inclusion can be conceptualised as good education (Jordan, 2005) and is about flexibility to understand and meet the needs of pupils. It is not about placing a child in a setting without addressing needs and it is not just about training a limited number of support teachers. The development of Resource Rooms in Palestinian schools has been admirable but may risk becoming a form of segregation and exclusion. Inclusion may require a variety of types of provision (Jordan, 2005; Wittemeyer, 2011) and Resource Rooms can be useful, but responsibility for children with additional needs, in a truly inclusive system, belongs to everyone, not just the Resource Room teacher. This is the premise of Terre des Hommes Inclusive Education project in East Jerusalem and their view of inclusion challenges the way in which Resource Rooms are used and perceived. Another perspective is held by the Friends of Autistic

Children Society who see no immediate inclusion possibilities for their children and young people and, instead, have an ambitious proposal for an autism 'village' similar to one established in Gaza by the Red Crescent Society. They have no funding to make this a reality but such a proposal for segregated provision is understandable when children with autism are excluded from the education provided for other children.

At a time when the validity of traditional and rigid teaching approaches are under scrutiny (Wahbeh, 2011; Al-Ramahi & Davies, 2002), it is timely to look at what inclusion can offer to this wider debate. Good practice in meeting the needs of children with autism can be seen as a model for thinking about the needs of all children.

The inclusion of children with autism requires us to view autism as a legitimate difference. If we hold the view that autism is a set of deficits to be put right, then our approach will differ from the approach we would take if we see autism as a different but equally valid way of being. Findings suggest that a medical model of autism predominates in Palestine and children with autism are seen as needing 'rehabilitation' or 'treatment'. The medical or deficit model of disability is strongly opposed by many people with autism in the West who call for greater social acceptance of diversity. Understanding the difference between the social and medical models of disability are fundamental to the way we address the needs of children with autism.

### **9.3.3 Building capacity for autism provision**

Early on I questioned the relevance of my research for Palestine. I have found that Palestinians value education and they also champion the rights of the child, as

witnessed by the full adoption of the Convention on the Rights of the Child by the Palestinian National Authority (PCBS, 2011). Research findings leave me in no doubt that the education of children with autism is a priority for Palestine. If prevalence rates are the same in Palestine as in the UK (Baird et al., 2006) then there are 12.500 or more children with autism in Palestine (based on 2010 population figures from PASSIA (2011))<sup>29</sup>. As well as the human rights of these children, enshrined in the CRC, there is an important reservoir of potential amongst these children whose unique skills and abilities can make them valuable members of society. At present the responsibility for children with autism falls mainly to the special centres that struggle financially. An inclusive education system would take responsibility for all children.

In addition to training, there are other resourcing implications. Inclusion of children with autism may require adaptations to the physical environment to enable them to access school. For example, a child with sensory processing difficulties may need a quiet place to retreat to, perhaps at break times, to avoid sensory overload.

The case study settings could stand as models of good practice in working inclusively with autistic children. Success indicators from the case studies compared with findings in the wider context (Table 45, p.246) offer a starting point for thinking about what is needed. Further to this, the AET National Standards (AET, 2015b) would be useful to generate debate on provision, practice and the removal of barriers.

#### **9.3.4 Collaboration**

Collaboration is a thread running through my study. Collaboration between

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<sup>29</sup> This estimate is much higher if based on the USA rate of 1 in 68 (CDCP, 2014)

professional groups, parents, communities and government departments is crucial in developing education for children with autism (Charman, et al., 2011; Prizant & Whetherby, 2006; Jones, G. et al., 2008), could lead to shared understanding or inclusion (Allan, 2008) and invigorate the teaching profession (Slee, 2001). In the search for answers collaboration came to dominate my thinking. Palestine thinkers also advocate collaboration (Wahbeh, 2011) and 'networking opportunities between schools and the local community' (p.48), seeing this as a way to empower professionals and develop practice. Research findings highlight a need for collaboration. Data set one indicates the isolation of parents and the lack of knowledge sharing between those with a stake in the world of autism. Data set two (MoEHE workshop) highlights a need for knowledge sharing and coordination of action through collaboration. The paired case study, described earlier as an 'embryonic CoP', gave an opportunity to witness the energy for learning inherent in peer-to-peer learning, pointing to CoP as a useful and empowering model for harnessing knowledge and developing practice.

In planning for the collaborative endeavour of a CoP, it is important not to overlook the real 'experts': internationally, parents have been the driving force for change in relation to autism practice and provision (Feinstein, 2010) and research has shown the importance of supporting and involving the parents of children with autism. Internationally, people with autism themselves have an increasingly strong and important voice within groups that seek to address their needs. My research did not find Palestinian individuals with autism who were able to be advocates for good practice but undoubtedly the potential is there for the future.



### **9.3.5 Identification and diagnosis**

The research showed considerable frustration about the lack of data on the prevalence of autism in Palestine and the low availability of reliable diagnosis. Although acceptance and understanding are more important than prevalence data (Kim, 2012), and provision for children with autism should be needs-led rather than diagnosis-led (DfES, 2002; NIASA, 2003), accurate statistics would give Palestine's strategists a useful measure on which to base planning and early identification of autism would provide parents and professionals with a useful signposts. The Friends of Autistic Children Society has proposed a multi-disciplinary diagnostic centre for autism. A welcome development is that such a centre has now opened, during the research, at An Najah University in Nablus.

### **9.3.6 Palestinians as creators of knowledge**

This research supports QCERD's maxim that the 'Palestinian people should become producers rather than mere consumers of knowledge' (QCERD, 2012) and champions autonomy for Palestine as it develops inclusive provision (Mittler, 2003). Palestine can and should contribute to the international discourse on inclusion. In the words of one interviewee: 'We are here on a small piece of land in Palestine but we still think ourselves able to contribute something ... on an international level'.

## **9.4 Recommendations**

In giving recommendations, I want to guard against the 'cook book' approach (Wahbeh, 2011). What I offer is not a recipe to bake a successful Palestinian autism inclusion cake. Instead, using a different metaphor, I offer some of the pieces of a

jigsaw and highlight opportunities drawn from my research findings. I am mindful of the many challenges faced by Palestine's decision makers and I respectfully put forward my recommendations.

#### **9.4.1 Knowledge, understanding and skills**

1. It would be valuable for Palestine to have its own autism specialists to guide developments; this could be achieved by the provision of scholarships for Palestinian teachers and practitioners to benefit from international expertise and gain high level qualifications in autism. The most authentic 'autism specialists' are perhaps those who are themselves autistic (Milton, 2014).
2. Culturally appropriate training materials would be a valuable asset. A starting point could be to translate and adapt the Autism Education Trust materials from the UK to suit Palestinian needs. In the UK these materials 'received overwhelmingly positive feedback from participants' (AET, 2013). The development of the AET materials came out of a successful collaborative partnership with practitioners, people with autism and parents across the UK and built on resources that had been developed in many different tried and tested locations. This is a working model for development that could perhaps be adapted for Palestine, with partners from across the country collaborating to develop materials and a strategy for Palestine. Following on from the small exploratory trial of these materials in Palestine during the study (Table 42, p.239), a Palestinian-led partnership to develop a similar set of materials, could involve parents, teachers, schools, kindergartens, ministries, universities, centres of provision, practitioners. This proposal is further developed below in recommendation 19.

3. Following on from the development of materials, an autism training team would be needed. Funding could be secured for a selected team of trainers to receive bespoke training to gain underpinning knowledge and use the training materials, so that they could lead a programme of training. A proposal made by Friends of Autistic Children Society was for the Autism Centre for Education and Research (ACER) at the University of Birmingham to establish a link in the West Bank in order to provide training for professionals. This could potentially be possible through securing an externally funded grant to enable collaboration.
4. Strategically planned regional training might offer training at three levels including:
  - Level One, **Basic** (awareness raising for everyone);
  - Level Two, **Intermediate** (for those who have regular contact with children on the autism spectrum);
  - Level Three, **Advanced** (for those who need or wish to know more: Inclusive Education Counsellors, Learning Support Teachers and Resource Room Teachers). This level could also provide more trainers.
5. Such a training model could include the development of a framework of competencies linked to qualifications. Again, this could be modelled on the AET National Standards and Competency Framework and adapted for the local context. (AET, 2015a)
6. A survey of Palestinian universities during the research period indicated that teachers had little or no opportunity to learn about autism or inclusive practices in their initial teacher education. This is a matter that could be addressed to

give future teachers the professional knowledge and skills needed to underpin inclusion in schools. There is further scope for specialist courses in autism.

7. Previous research (Farrell, 2007) called for the advanced training of IECs in special educational needs and I believe this is now taking place. It would be useful to ensure that autism and inclusion are a prominent part of this.
8. Parents need access to knowledge and skills. Friends of Autistic Children Society proposed a partnership to develop a portfolio of materials for parents. Materials for parents could be translated and adapted for Palestine. Permission has been given to use Right Click, the UK programme developed by Scottish Autism. Parents themselves should be involved in this development.
9. Further translation of carefully selected materials into Arabic could give parents and professionals access to written information. This has already been proposed by QCERD and the most appropriate materials need to be identified.
10. Judicious development of a Palestinian web forum related to autism would allow parents and professionals to share information and areas of concern.
11. Participants spoke of a wish to travel abroad to observe and learn from good practice from other countries. It was also suggested that there should be exchange visits for practitioners and teachers between Palestine and the UK. These ideas suggest a good opportunity to learn from and contribute to international developments in autism.

#### **9.4.2 Reconceptualisation of inclusion**

12. There needs to be clarity and a shared understanding of inclusion through a process of debate and discussion amongst educators, practitioners, parents and decision makers.

**13.** The topic of inclusion could be embedded within all programmes for teachers.

QCERD have proposed this for their programmes, and this could offer a model for others involved in teacher education.

**14.** Discussions and debates in the field of autism and inclusion need to take careful account of the language and concepts they use.

#### **9.4.3 Building capacity for autism provision**

**15.** Greater oversight and support for the centres by government departments would bring the children in these centres a step nearer to being included and pave the way for greater fluidity of provision between the centres and the schools.

**16.** A small pilot project in one school, could build on what has been learnt and achieved elsewhere. Participants in the two focus groups expressed willingness to support other schools wishing to include children with autism and this gives a valuable resource on which to draw. Early intervention is important for children with autism (Guldberg, 2010; Parsons, et al., 2009) and so this might be a good starting point. Sustainability of initiatives is an issue in Palestine.

**17.** The workload of IECs is too high for them to be truly effective. I concur with Farrell's (2007) recommendation to vastly increase their numbers and develop their expertise to enable them to give better support for inclusion. This could be a long-term goal as there is clearly a cost implication. In addition it would be valuable to create an autism specialist team within the Inclusive Educational Counsellors.

**18.** The presence of support teachers was identified in this research as one of the factors contributing to successful outcomes in each of the two settings. This adds weight to Farrell's (2007) call for support teachers to be employed in government schools to support the inclusion of children with additional needs.

#### **9.4.4 Collaboration**

**19.** A community of practice, bringing together parents, members of the community and professionals could come together with a shared commitment to develop autism practice in Palestine. Ideally it would include autistic people. The catalyst for this could come from a number of possible sources: government, parents, teachers, practitioners, non-governmental trusts or academic bodies. There is also a need for collaboration between government departments.

#### **9.4.5 Identification and diagnosis**

**20.** Diagnosis is an important issue that needs to be addressed. Autism is an issue that crosses boundaries between professional disciplines and it requires collaboration at government level to put in place a plan of action to address and resolve the issue of diagnosis.

#### **9.4.6 Palestinians as creators of knowledge**

**21.** A logical progression from my research would be for a partnership of the participants, and others, to join forces in a project to develop knowledge, practice and culturally appropriate resources and to devise a development strategy for Palestine. There is an opportunity to build on my study with a

funded research project in collaboration with the Autism Centre for Education and Research (ACER), building on the methodology and approach that ACER developed for their current 'Transform Autism Education' international project. The focus should be to prioritise areas that benefit the lives of people with autism and their families and it should involve autistic people and their families (Pellicano, et al., 2014; Milton, 2014)

### **9.5 Relevance of the research**

My research is unique within Palestine, and possibly in other parts of the Arabic-speaking world too. Despite the limitations discussed below, I am hopeful that it provides clearer understanding of education and inclusion of children with autism in Palestine. Looked at through a lens of international practice, my study offers a contribution towards the development of good autism practice in Palestine. This is an undeveloped field in Palestine, and QCERD which sponsored my research has indicated an interest in building on my work. I have also been able to establish positive relations with the Palestinian Ministry of Education, through my involvement with them and they have requested that I provide them with recommendations from my research as a basis for development. In addition, the practitioners that I worked with in my research are willing to take a role in promoting good practice more widely within the region. On these three fronts there is a strong potential for long-term and sustainable impact from my research. In addition, two Palestinian universities, An-Najah University in Nablus and Ahliya University in Bethlehem, are beginning to make developments in this field and possible collaborative links with Autism Centre for Education and Research (ACER) at the University of Birmingham could be strengthened as a result of this research.

## 9.6 Limitations

One limitation of my study is geographical in that it has not been feasible for me to include Gaza in my research although over a third of the population of Palestine is in Gaza (PASSIA, 2011). Therefore my study has been confined to the West Bank and East Jerusalem; but even there I was unable to visit all areas, and so my research into the wider context is far from complete.

Another constraint is that my case study is limited to two private schools, and although they are very different from each other, it is a drawback that a government school was not included. Also, I did not include UNRWA schools in my study, although for over sixty years they have played a significant part in educating refugee children within Palestine and within the wider Palestinian diaspora<sup>30</sup>.

I was working in a different culture and despite the welcome support of a translator, I do not understand the Arabic language. As well as practical and ethical concerns (Laws et al., 2003), this presents a challenging barrier to the interpretation of nuanced meanings (Bellos, 2012), especially as the field of research, autism and disability, is one where language use is dynamic and changing. This has been an interesting challenge for the research.

Another limitation is that I was unable to obtain data by talking with Palestinian children. This was largely because of my inability to use Arabic, and the feeling, after talking with the adults involved, that for children prone to anxiety, unsettled by change and unskilled in social interaction, trying to converse through a translator with a foreign researcher would be a step too far. I tried to overcome this and thereby

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<sup>30</sup> UNRWA currently teach over 50,000 children in 99 schools in the West Bank and over four times that number of children in Gaza (UNRWA, accessed 2015).



have access to the child's voice by encouraging the teachers at FGS to elicit children's opinions in the assessment profile that they tried out. However they did not attempt this. Possibly this is not something they were familiar or comfortable with. A similar limiting factor is that I listened to no autistic Palestinian voices during my research as it proved impossible to identify any. This is a significant gap in my research as, from a western perspective, it would now be unthinkable to carry out a research project like mine without the involvement of autistic people.

## **9.7 Reflections on the research process**

As well as learning from the data, I learnt a great deal about the process of collecting that data and there are things that I would do differently if I could start again.

### **1. Questionnaires as a research instrument**

The time spent studying the research literature and designing my questionnaires had limited payback in terms of providing reliable data. This was exacerbated by the need for translation – a twofold process of translating the questionnaire into Arabic and then translating the responses back into English. After my assiduous attention to the wording of questions to ensure clarity, I was hostage to the skills of my translator in obtaining semantic equivalence. I believe that using questionnaires as a research instrument to cross language boundaries would benefit from a higher level of robust expertise provided by a team of skilled translators who were also familiar with the terminology associated with the research topic. Even the presentation of the questionnaire is affected by translation: The Arabic translation takes up more space than the original English and it goes from right to left, so careful attention to the look of the thing by the originator can be undermined by the process of translation. There

is also the question of cultural perceptions of questionnaires. My impression was of a reluctance to engage with the questionnaires and I was left wondering whether there was a culturally-related antipathy to questionnaires. On reflection, I realise that although I enjoyed the challenge of designing the questionnaires, I myself dislike the formality and restrictive nature of completing questionnaires. I would be far more circumspect about using questionnaires in future. Where I felt my use of a questionnaire was far more useful in providing rich data was in the MoEHE workshop where, taking a lesson from my previous questionnaires, I used a very simple questionnaire with three short open questions and, importantly, issued it and collected it in after ten minutes at the beginning of the workshop so that I had a captive group of respondents and made a limited demand on their time.

## **2. Role of the researcher**

I believe there was an ambiguity in my role, both in my mind and in that of my case study participants, and that this was not helpful. My research design was exploratory, interpretative and emergent, making me perhaps too vague about the boundaries of my role and my expectations as a researcher. Despite my explanations given verbally and in the participant information documents, I believe that I was primarily seen by some people as a bringer of knowledge from the cornucopia of overseas donors and NGOs, rather than a researcher seeking to work collaboratively. I had played down the fact that I was doing a PhD (an MPhil to start with) as this, to me, was not the purpose of my research, which was to do something useful for Palestine. However, as the need for data became more pressing, it may have seemed like a deception that I had not been more transparent about the fact that I was working towards a personal qualification and it may have seemed that I was motivated by

self-interest rather than a wish to support them. I suspect that I should have been clearer about this from the outset. The research process has left me with a huge sense of responsibility towards my Palestinian colleagues, and I do not want it to be that I have left what I seemed to offer them incomplete.

### **3. Technology**

I envisaged technology as a valuable tool in my research. In many ways it was: emails enabled me to maintain contact with key people; for interviews I used a digital recorder; my computer helped in the production of research instruments and resource materials. It was less than helpful, however, for the skype meetings that I had planned to hold with case study participants. The difficulty seemed to be because of poor internet connectivity in Palestine. I had not anticipated this and it limited the useful contact that I was able to have. The other area which was less successful that I hoped was in the development of the Wiki. Such a tool held the potential to overcome the regional fragmentation of Palestine and enable participants to share and communicate, or so I thought. In reality it was not taken up as much as I hoped and I have discussed the possible reasons for this (p.226). However, it provides a record of the resource bank that we developed and it would be valuable to explore the possibility of creating a more useful shared online space for the sharing of ideas.

### **4. Language and culture**

From the outset I was aware that the issue of language and culture would be a major challenge and a limitation. I discussed this issue at some length in my research design chapter and wrote about the need to limit the possible contamination of my data by faulty translation. It was even more taxing than anticipated and a sense of

the complexity of this and the need for checking and double checking for accuracy is conveyed in my field notes (Table 56).

Extract from field notes (3/12)
<p>The translated questionnaires from the Ministry workshop were returned to me by email after I had returned to the UK so there was no immediate opportunity to sit down with my translator to clarify meanings. I collated responses for analysis but, looking at the translations I was not always convinced that they were accurate. For example, the translations showed that a number of people had given 'loneliness' as a feature of autism. Did they mean this or had the original Arabic been wrongly translated? Had they perhaps meant 'aloneness' or 'solitariness' or 'isolation'? This uncertainty about the translation was repeated many times and it was unsettling. In some cases, the translation was not given in idiomatic English and I could make a guess at the meaning but this approach lacked rigour and I needed to find a way of being more certain about the intended meanings. Of course there was always the possibility that some of the participants had given obscure answers even in the original Arabic. I needed to check. So this is what we did:</p> <p>I annotated the collated responses with my queries. Where I was uncertain about the true meaning of a word or phrase, I emboldened the text and where I suspected that different wording might give the true meaning I wrote this in red next to the translation. I then asked the translator to look at it again and asked her to write in blue with her comments and where she agreed that my suggestions gave a more accurate meaning, to change them from red to blue. Where my suggestions were wrong I asked her to give a clearer translation. In this way we clear up many of the difficulties and there was further email correspondence before I felt confident that the data was reliably translated.</p>

Table 56: Extract from field notes (3/12)

I did my best to safeguard the validity of translations in numerous ways as described in Chapter 5 and I believe this went some way to overcoming this limitation.

**9.8 Dissemination**

A detailed report of my study (Ashbee, 2013) has been translated into Arabic and published in Palestine. I presented my research to a group of over 60 people at a

study day set up for the purpose in Ramallah in February 2005. It attracted media coverage and was reported in the Palestinian newspapers and television. I am currently working on a paper together with Dr Karen Guldberg, my supervisor, on educational inclusion for children with autism in Palestine. I am hopeful that my thesis will be translated into Arabic.

### **9.9 Concluding note**

With humility I put forward my thesis. I hope that it can be a useful contribution towards the endeavours of parents, teachers, practitioners and communities in Palestine who wish for a better life for their autistic children. I think again of Handala, voiceless, faceless, excluded; I think again of Ahmad and other children like him; I think again of friends and colleagues in Palestine; and I imagine the day when voices that should be heard, are heard and when Handala, Ahmad and Palestine are included so that they can fully belong and participate in the world.



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## Appendix 1: Initial staff questionnaire

### Educational Provision for Children on the Autism Spectrum - Questionnaire for teaching staff and classroom assistants -

This questionnaire is part of a research project which is looking at the educational provision for children on the autism spectrum in Palestine. Your school has agreed to be a partner in this research which is supervised by the Autism Centre for Education and Research at Birmingham University, UK and is supported by the Qattan Centre for Educational Research and Development, Ramallah.

Your contribution is much appreciated. You may remain anonymous if you wish.

Please return your completed form to the school office by \_\_\_\_\_

**Q1 Where might you go for advice in understanding the needs of a pupil in your class with special educational needs?**  
(please tick as many as are appropriate)

Office use

- |                           |                          |                          |                          |
|---------------------------|--------------------------|--------------------------|--------------------------|
| Special needs coordinator | <input type="checkbox"/> | The parents              | <input type="checkbox"/> |
| Headteacher               | <input type="checkbox"/> | Outside professionals    | <input type="checkbox"/> |
| The Internet              | <input type="checkbox"/> | I would not seek support | <input type="checkbox"/> |
| Other (please specify)    | <input type="text"/>     |                          |                          |

**Q2 Do any of the children with whom you work have a diagnosis of an autism spectrum disorder (including Asperger Syndrome)?**

Yes ☐ How many ☐

No ☐ I don't know ☐

Comment  
(optional)

**Q3 Have you had the opportunity to learn about autism: (please tick)**

- |                                   |                          |                                     |                          |
|-----------------------------------|--------------------------|-------------------------------------|--------------------------|
| • during initial teacher training | <input type="checkbox"/> | Approximate number of days training | <input type="checkbox"/> |
| • during in-service training      | <input type="checkbox"/> | Approximate number of days training | <input type="checkbox"/> |
| • other (please comment)          | <input type="text"/>     |                                     |                          |

<p><b>Q4 Children with autism should be included and taught alongside their typically developing peers.</b></p> <p><i>Tick the appropriate box</i></p>	<p>Strongly agree <input type="checkbox"/></p> <p>Agree <input type="checkbox"/></p> <p>Neutral <input type="checkbox"/></p> <p>Disagree <input type="checkbox"/></p> <p>Strongly disagree <input type="checkbox"/></p>	<p>Office use</p>
<p><b>Q5 In my understanding about the autism spectrum I feel that:</b> (please tick one box)</p> <div style="display: flex; justify-content: space-around; align-items: flex-end;"> <div style="text-align: center;"> <input type="checkbox"/> 1 I am very knowledgeable         </div> <div style="text-align: center;"> <input type="checkbox"/> 2         </div> <div style="text-align: center;"> <input type="checkbox"/> 3         </div> <div style="text-align: center;"> <input type="checkbox"/> 4         </div> <div style="text-align: center;"> <input type="checkbox"/> 5 I have no knowledge         </div> </div> <div style="text-align: center; margin-top: 10px;"> </div>		
<p><b>Q6 To what extent has your training prepared you for meeting the needs of the average child you work with.</b> (please tick)</p>	<div style="display: flex; align-items: center;"> <div style="text-align: center;"> <p>Not at all</p> <p>a</p> </div> <div style="flex-grow: 1; text-align: center;"> </div> <div style="text-align: center;"> <p>Very well</p> <p>e</p> </div> </div>	
<p><b>Q7 To what extent has your training prepared you for working with children</b></p> <div style="display: flex; align-items: center; margin-bottom: 10px;"> <div style="text-align: center;">a</div> <div style="flex-grow: 1; text-align: center;"> </div> <div style="text-align: center;">e</div> </div> <p>7.1 Understanding the strengths and difficulties of a child on the autism spectrum</p> <p>7.2 Using appropriate strategies to support the learning of a child on the autism spectrum</p> <p>7.3 Developing social understanding and interaction in a child on the autism spectrum</p> <p>7.4 Using strategies to help a child on the autism spectrum to cope within the school environment.</p> <p>7.5 Using strategies to help a child on the autism spectrum to communicate.</p> <p>7.6 Promoting appropriate behaviour in a child on the autism spectrum</p>		

**Q8 I would like the opportunity to develop my skills and knowledge for working with children on the autism spectrum.**

*Tick the appropriate box*

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

☐☐☐☐☐

Office use

Comment  
(optional)

**Q9 Additional Comment (optional)**

**Q10 Personal details:**

Name (optional)

Teacher

☐

Classroom  
Assistant

☐

Other

School

**Q11 Are you willing to be contacted for further information about your answers? (Only possible if you have chosen to give your name)**

Yes

☐

No

☐

**Thank you very much for your cooperation.**

## Appendix 2: Interview schedule –community providers

INTERVIEW SCHEDULE – Community Providers		
Topic	Possible questions	Probes
<b>Recording of interview</b>	I would like to record our conversation? Is that OK with you? (explain confidentiality / anonymity)	
<b>Organisation</b>	Who is involved?  How do you operate? Are there regular meetings?  Mission / policy? Written?  Funding and support?  History? How did it come about?  Approaches?	Geographical differences / liaison?  Links with the PA?  Government finance?  Driving forces?  Successes?
<b>Provision</b>	How do children access the provision?  What is the range of needs? (HF / AS / SLD?)  How many children attend / how long can they stay?  Training / knowledge /expertise?  Locations and facilities?  How well do you feel that they understand the children's needs?	Do parents pay? Selection?  Examples of success?  Other providers that are not within the Coalition?  Are educational approaches used ?
<b>Education</b>	Have some of the children attended school and had to leave?  Have any children been able to progress from the group to school?  Do you feel that schools should cater for these children?  Do the parents feel that their children should be able to attend school?  Do you think that the Ministry policy on inclusion extends to ASD?	What age does this happen?  Do most children go to school in Palestine?  What needs to happen?
<b>Autism in Palestine</b>	Is it possible to get a reliable diagnosis of autism?  What expertise is available?  Is training available for professionals? (Medical, SaLT, OT, Education)  Are there any preferred approaches to the 'treatment' of children with autism?  What happens to adults with autism? Is there and support?	How is it done / by whom?  Where and to what level?
<b>Social attitudes</b>	Could you talk about social attitudes towards ASD or towards SEN in general?  Are attitudes changing in any way?  Parental attitudes?	Acceptance?  Stigma?  Religious dimension?
<b>Change / development</b>	What changes and developments would you like to see?  What do you think might be a good successful outcome for this research project?	How could that be achieved?  Barriers to success?

**Appendix 3: Participant Consent Form and Right to Withdraw (School staff)**  
**Research Study: Developing educational provision for children with autism in Palestine**

**Name** \_\_\_\_\_

Please tick to indicate you understand and agree to the following:

I have read and understood the participant information	<input type="checkbox"/>
I understand that all information will be kept securely and will be confidential	<input type="checkbox"/>
I know that I am able to ask questions about the study	<input type="checkbox"/>
I understand that this is an invitation and I don't have to take part	<input type="checkbox"/>
I understand that I can withdraw at any point without giving a reason, and my information will be removed from the study	<input type="checkbox"/>
I understand that if I choose to withdraw from the study this will not affect my employee rights or my access to training in any way	<input type="checkbox"/>
I agree to discussions and meetings being audio or video recorded and transcribed	<input type="checkbox"/>
I agree to classroom observations carried out by the researcher and research assistant, where appropriate	<input type="checkbox"/>
I agree to anonymised material being used within the researcher's thesis and other publications	<input type="checkbox"/>
I agree to take part in this research study	<input type="checkbox"/>
I would like to take part in:	
• The questionnaire	<input type="checkbox"/>
• Workshops	<input type="checkbox"/>
• Focus group	<input type="checkbox"/>
I would like to be listed in the acknowledgements of any publications or reports although my name would not be related to any specific data:	<input type="checkbox"/>

**Researcher's contact details:**

**Research Assistant's contact details:**

**Research Supervisor's contact details:**



## **Appendix 4: Participant information – school staff**

### **Developing educational provision for children on the autism spectrum in Palestine**

#### **What is the research about?**

The research project will work with the staff of two elementary Palestinian schools that have accepted an invitation to work with me to develop their practice for pupils who are on the autism spectrum. Building on existing knowledge we will work together over two years, setting goals, providing learning opportunities, reviewing progress and setting new goals.

#### **Who is the primary researcher?**

Elaine Ashbee is a specialist advisory teacher from the UK where she has worked across many schools to support and guide staff in meeting the needs of children with autism spectrum disorders.

#### **Who is the research assistant?**

\_\_\_\_\_ will be working closely with Elaine to support this research.

#### **How will this research be supervised?**

It will be supervised by Dr Karen Guldberg who is the Director of the Autism Centre for Education and Research at Birmingham University.

#### **How will this be supported?**

The Qattan Centre for Educational Research and Development in Ramallah is supporting this project by providing advice, essential funding, administrative support, translation, materials and facilities.

#### **What will I be asked to do?**

You will be asked to complete a questionnaire about your knowledge and experience in relation to autism. It can be anonymous if you wish and any information that you provide will be confidential.

A few key members of staff will be asked to take part in interviews. If you agree, our discussion will be audio recorded. Information provided will be confidential.

There will be the opportunity to be part of a focus group that will meet at agreed times over the two years.

There will be workshops about the autism spectrum and educational provision during the two years and you will be invited to attend.

If you have a pupils with autism in your class, I would like to visit and observe your class, if you agree.

#### **Do I have to participate?**

No. Participation is optional. You may choose to participate in some aspects and not others if you wish. There will be no problems if you choose not to participate.

#### **What if I decide to withdraw?**

You will have the right to withdraw at any time.

**What happens to the information?**

Information, including audio recordings,, will remain confidential, available only to authorised researchers for verification purposes and will be kept securely for ten years, after which time it will be destroyed.

**Where can I get further information about this?**

Elaine Ashbee (Primary Researcher):

Karen Guldberg (Research Supervisor, University of Birmingham):

**Appendix 5: Introductory questionnaire (MoE workshop)**

Things I know about the autism spectrum	
Things I know about supporting a child on the autism spectrum	
Things I would like to know	
Name (optional)	Role

## Appendix 6: Observation and assessment profile

Student: \_\_\_\_\_ Year \_\_\_\_\_ Date \_\_\_\_\_

To be based on observation in a variety of settings and information obtained from parents and staff who know the child well.

Social Interaction		Significant difficulty	Some difficulty	No difficulty
1	Joining in an activity with other children			
2	Sharing attention with other children			
3	Understanding and sharing emotions			
4	Developing friendships			
5	Showing empathy			
6	Understanding another person's point of view			
7	Anticipating and understanding the behaviour of others			
8	Understanding social rules			
9	Behaving appropriately in different situations			
10	Taking turns			
11	Showing awareness of status			
<b>Comments:</b>  				
Social Communication		Significant difficulty	Some difficulty	No difficulty
1	Using language for a variety of functions			
2	Taking part appropriately in a conversation			
3	Being aware of the listener's needs			
4	Using facial expression and eye contact			
5	Using body language and gesture conventionally			
6	Understanding spoken instructions and information given individually			
7	Understanding spoken instructions and information given to the class			
8	Understanding other people's use of facial expression, gesture and body language			
9	Understanding abstract and non-literal language			
10	Understanding implied meaning			
<b>Comments:</b>  				

Flexibility of thought				Significant difficulty	Some difficulty	No difficulty
1	Accepting changes to routines					
2	Accepting changes to the environment					
3	Transferring skills to new situations					
4	Switching attention from one task to another					
5	Taking part in pretend play with others					
6	Making choices and making decisions					
7	Planning and organising					
8	Solving problems					
9	Restricted, obsessional or very strong interests	Yes		If yes, give examples:		
		No				
<b>Comments:</b>          						
<b>Sensory differences (Use Sensory Check-list as a basis for your comments)</b>						
<b>Comments:</b>          						
<b>Emotional Regulation</b>						
What activities are most enjoyable or interesting to the child?						
What activities create distress or are boring to the child?						
Does the child use any calming strategies (eg. rocking)						
Does the child respond to comfort offered by others? If so, how?						
How do you know if the child is overwhelmed or upset? What are the signs?						
<b>Student's contribution:</b>          						

<b>Support</b>	
What strategies have you found to be most helpful? (eg. to secure the child's attention, to support communication, to cope with problem behaviours.)	
<b>List child's main strengths</b>	
<b>List difficulties / concerns</b>	
<b>Other important information about the child</b>	
<b>Those involved in making this assessment ( 'parent', 'teacher', 'support teacher' etc.)</b>	

Signed \_\_\_\_\_

Date \_\_\_\_\_

Pilot assessment form devised by Elaine Ashbee with ideas borrowed from The SCERTS Model (2006)

## Appendix 7: Transcribed interview – Parent – an example

H\*\*\*\*(K\*\*'s mother) October 2011 (recording in 2 parts)

00	I am pleased to meet you..... I like this kind of research
2.14	I discovered that K** had a sort of autism when he was 1 year and 6 months. When we talk he doesn't look at us. He was making strange moves like turning around himself. Sometimes he was walking in a straight line and also doing reverse in the same line. Some strange moves that make me feel suspicious. So I started a search on the Internet about these moves and why he didn't look at me when I talk to him. He was my first child. He was a premature baby. He was 36 weeks, born after 6 months only. He stayed in the incubator for 3 months and his health was sometimes dangerous. The hospital was in contact with us and they were telling us that K** may not continue in the life.
4.13	The hospital was in Mukhsak hospital (?) in Jerusalem. I have difficult circumstances because I wasn't have a Palestinian ID because I am Jordanian. It was closure in Ramallah so it was difficult to reach Mukhsak ? Hospital. When I feel that I have to get the baby the hospital in Ramallah sent me to the hospital in Jerusalem. At the checkpoint it wasn't easy to pass. They asked me for the Identity and I don't have Identity. The driver of the ambulance he talked with the soldiers and he told them this woman will get a baby now. She must now go to the hospital. Finally I got to the hospital and when I got there I had K** in 20 minutes. They put him in the incubator and I stayed with him in the hospital for three days. He was one kilo, like a bird. In the hospital they advised me to get my own milk for K** but I don't have milk because it was 6 months only. So I tried very much to get my milk. I was pumping. Then I get back to Ramallah and K** stayed in Mukhsak and for three months I didn't see K**. He was alone in the hospital. I couldn't see him because it was very difficult to go to Jerusalem. It is difficult for all Palestinians but for me it is more difficult because I don't have the ID. There is no room in the hospital for the mothers. It was very difficult for me and for K** maybe more. Then I was sending my milk. His father was going to the hospital every Friday and he took the cans of my milk. I put my milk in the refrigerator and every Friday I was sending it.
7.54	Then the hospital (after 3 months) called us and said K** is good. You can come and take him. I went through villages and walking through the streets to reach the hospital. I got K** and we returned to Ramallah in the same way, walking, around the checkpoints. I walk through villages where the soldiers cannot see me [ ] When I reached home the hospital was advising me what to do with K**, how to feed him. They told me it is necessary to make the room very clean.
	Interruption
Rec 2	I told my friends not to come to the house and not to see K**, and to my relatives. Why? Because I was so afraid. He was so sensitive and he catch the viruses very quickly. But now he is very ok. After a year I noticed what I told you about his moves. When I talked to him he didn't repeat the words, he didn't look at me. He likes to catch some objects in his hand and he was insisting to catch them but he doesn't know what to do with them. I was sure that he hear very much. I was sure because he liked some songs from the television and he was looking at the television for maybe 4,5 hours continuously without looking around him, only on the TV. More than one think I noticed about K** and made me think maybe he's not normal.
2.01	<i>Had you heard about autism before you had K**?</i> No. I don't hear about autism before K**. Then another difficulty started. The most difficulty was to convince his father that he's not all right. His father was: 'No he's normal. Don't make me afraid'. Then I suggest to my husband to take K** to the doctor. We took him to a specialist in nose and ears. The doctor told us he has some liquid in his ears, but this doesn't mean that he doesn't look at you. This is another think. So you have to go and check his hearing to another special hospital in Beit Jala. [IT] is a hospital about checking the hearing and checking the brain to make sure that he hear. The test was ok. K** hear very much and nothing wrong with his hearing. I was sure of that because he was interested with the songs. After this I suggested to my husband that we should take him to the centre that specialises in special needs, in Jenara (??) and this centre is in Ramallah.
5.18	The boss of this centre is a woman. She played with K** and she tried to hide and she made more than a test for K**. Finally she said it is so early to get K**. He was 1 year and 3 months. Take him home and let him have breakfast and lunch and dinner and let him sleep in another room. I wan't convinced of this so I took K** to another doctor, a neurologist, and he also made some tests. He told us that it is so early, wait another year as he is premature. He told us that everything about his nerves is ok. He look and he interact with him. Then I took him to a general doctor for children. This doctor said yes you are right there is something not normal with K** because the mother is the only person who knows about her child. So he have me the name of a woman she's a psychologist for children, she's French. For my good luck, I know her father, he was a boss in my work. So I called the father and she's working in the hospital for special needs children. She came to Ramallah more that 3 times to test K**. She brought with her the test which she said is the standard test for autistic children ( maybe AB). She told me this test is too early for K** but because you insist to do it I will make it. The questionnaire was, most of it, for the parents. She asked me maybe 10 questions and came another time and asked other questions. It was like if I noticed when K** was a baby if he noticed the toys that were hanging on his bed. I remembered that, no, K** was not interested and not only that, he didn't like to look at these toys. Also he refused to look at teddy bears and toys that have eyes, every toy that has eyes, especially animals. It was very obvious. But now everything is changed.
10.02	She told me that K** is not normal. I told her that K** is autistic. She said maybe he is autistic but I am not sure because he is too young and because he's premature. She advised me to take him to a centre for speech therapy and to put him in a nursery to play with children. I was working in the University of Birzeit, I' a computer programmer, and my position was very good, but I left all my life for him. I stayed with him at home, but she told me that this will not help K**. K** should go to nursery and you should look for work. And so I registered K** for speech therapy and also K** went to a high level nursery to pay attention to K**, to teach him how to go to bathroom and how to eat himself. These two things made a most change for K**. They were very helpful for K**, especially the nursery. The first few months he played by himself. He refused to play with children; he refused to interact with his teacher; he refused to eat their food. He only liked zeit w zaatar, oil and zaatar. After a year in the nursery he eats their food, he plays with all children, and the teacher told me that he's very clever. She was

	teaching him letters in English, letters in Arabic and she said he's very clever – high-level thinking, more than his age. He stayed in the nursery and the speech therapy centre for 4 years, in Ramallah, Sp Th C: Annahda (??); Nursery: Baby World. It was too expensive for us.
14.41	[No special interventions for K**]. They have a Montessori style of nursery. They paid attention for K** but not to make for him a special kind of environment. The same environment for all the children including K**. He made a lot of progress but it was very expensive for us because I left my work. My husband was still working in the Palestinian Authority and the salary is not too high. After that I called the psychologist and asked her that I'm afraid K** would not go to school like all children. She said you have to think that maybe K** cannot go to school. It was depressing for me to think that my first child may not go to school [because of his] special needs and I will stay at home with him all my life. It was very depressing until I heard about Friends school where they have a special department for children with special needs. So I called Miss Salma Khalidi who was so interested. I thank her very, very, very much because this was the most important event in my life that K** comes to school and I thank Salma for this. The first year in KG1 there was no free space for K** so Miss Salma told me to stay for the coming year. She told me that this is also for the benefit of K** because he is too young and he is premature. I don't mind. He was in the nursery and I was monitoring his progress and everything was OK. Also in the speech therapy the lessons were scientific, because when I was looking at the Internet and following up with this Sp Th Centre, they were following the instructions for how to deal with autistic children, like, the autistic children learn by painting or something like this. [From checking on the Internet] I was sure that it was OK and it was high level and developing with the world, up-to-date. I tried with many parents here in Palestine to make a society for autistic children. I got names from the sp th centres and I called mothers to start doing something. I called another Israeli centre in Tel Aviv, I explained that we need something in Ramallah, that we have too many autistic children. I felt that they wanted to bring our children there and have payment, to make money out of it. So I neglected the idea of making contact with Israel because there is a difficulty that we cannot transfer between Ramallah and Israel, but I know that Israel is a very developed country in this sector because I searched on the Internet. In Palestine, for all kinds of special needs we are weak. We are weak for human rights. When I called the parents some of them were encouraged and we made many meetings and we started to work for this society. We went to the Ministry of the Interior and we [got] a licence for this society. We booked a small building [from] a person that is living in America and we used his house for this purpose. This house is in Surda – Autistic Children Friends Society.
23.15	With Iyad Ladadweh. I started this but now I have no relations with them. I started with a woman called Buran, her son is now maybe 15, but she left the country and went to Norway for her child. She got depressed because all NGOs here and the donors only want to make money, not to pay attention for our children. So she went. I cannot continue because I have another baby, she's called [REDACTED], she's now in KG2 here. It was hard to go on and my husband was nervous with taking children to Surda and coming from there. It was winter. So briefly, I left them and returned back to home. I heard from them that the centre now has activities, speech therapy maybe, occupational therapy and something like that.
25.32	The mother makes everything possible for her child. Internet I search how to complete my study in autism. I really think how to leave the IT and specialise in this sector in life because I have practical experience, not only theory. I was interested to complete my study in autism so I go to the website of Birmingham. What kind of classes they have. I was interested to make correspondence with them but then I have to work here to get money for K** for the school because the school is so expensive and for my daughter also. I still work in my specialisation, IT programming.
27.22	<i>Birmingham?</i> Didn't have any correspondence. I know they do on-line courses. Hopes to do something in the future.
28.08	<i>Who gave the diagnosis?</i> The French psychologist from Bethlehem. She said he may be on the autistic spectrum. Through my work with the society I met someone from Hebron who specialised in autism. He was making his high studies in America in autism, a research student. He liked to work with us in the society and I think he was looking for a job for himself. He saw K** and told me that K** has a kind of classical autism for sure. I agree with him.
30.28	<i>How did you feel when you got the diagnosis?</i> I was depressed at first. A doctor came from Uppsala, Sweden, called David Henley who specialised in autism. He's too old, 60 or more than that. He has a long experience of autism in Sweden. He came to Palestine. He made some projects for the sen children and how to teach the supervisors. One time he called me to come and introduce about my child. The doctor asked me to bring him to diagnose him for free. He said that K** has classical autism for sure. My husband was so upset. But now I am not sad because K** is a genius. I will not tell you he is HF, no he is not HF, but he is very clever. Maybe he is high functioning in some lines. Now my husband has accepted it. He loves K** too much. Everywhere he is talking about K** all the time. [the community and the family] accept and love K**. We are proud of K**.
33.41	<i>What approaches have you found to be useful for him?</i> I'm convinced that music is very helpful for K**. He has musical ears and his hearing is very sensitive. He repeats what he hears in the same way exactly. Music, sounds, voices, he repeat everything very clearly in an exact way. He sings at home – what he listened for the TV or in school. Music is good for him but his father doesn't accept the idea because we don't have money to make him go into a centre for music. I play piano but now I haven't much time to teach them. When he was young, because he liked the straight lines very much, I concentrate in making his teaching in straight lines. I went to the market and bought cards with different paintings – lion, apple, banana and put them on the ground in straight line and I started to teach him how to talk these words. He loves this game very much – to put things in a straight line, so it was very helpful for K**. I find out what he loves. I teach K** what I want to teach him but in his way: in straight lines, in singing, in his way, not the standard way. He likes playing with sand so I got sand and make shapes with sand and taught him this is a rectangle, a square and he was learning very much. I used the materials and the ways he loves. And everything that he doesn't like or refused to look at, I didn't mention that for him – teddy bears or things like that. I have just used my own feeling and from the Internet to help him.
38.46	Everywhere he go he wants to take me with him. He loves me very much. In his first 4 years he preferred to play alone and not interact with his relatives. He has changed now very much. He interacts with our relatives very much. He plays with children and with his sister. When she is alone, he comes and play with her.
40.1	<i>What are his main difficulties?</i> He doesn't understand what the call (?) of this game, for example. When he plays with children – all of them run in the same



	<p>direction and he runs with them but sometimes he doesn't know what's the meaning of this game. This sometimes makes children refuse to play with K** because he doesn't know the meaning of the game. So he has a problem [in making friends] In our village we went at the weekend. We have in the family maybe 50 children. His sister plays with them all but he doesn't play with them or if he plays with them they sometimes go far away. <i>Does this upset him?</i> No it upsets me but not him. He prefers to be alone. It's good for him to be alone and take the toys of other children and play alone with them. I hope that [he can develop his social interaction and ability to play with other children]. I cannot make this change for K** because his nature is like this. He is happy by himself but I am not happy because I will die and he will stay alone in his life. I just want him to understand people, to play with them. This is my main fear. I want him to understand what people say and what they do with others.</p>
43.24	<p>Social progress is more important for K**. Here in Palestine... Most guys in Hebron they didn't learn but they make more money that the learned [educated?] people. They make so much money. Certificate here is not the important thing. I am interested in education but i know this is not the most important for the person</p>
45.01	<p>He likes the computer very much. He play games on the computer. He is now interested in soldiers and guns which is suitable for his age. Other mothers have told me that all boys this age, 7, like guns, war and soldiers. He likes drawing very much and is very good at it. I used this to teach K**. He liked to learn by drawing. Even now, when I feel he doesn't understand the lesson in school, I draw the lesson for him. He has very good visual memory and very good listening memory. When he heard a word, before maybe 5 years, he will not forget that. He understands well when I talk to him but I don't know whether he understands other people. In the class – I don't know whether he understands everything. His teacher told me he is excellent. He works well and he interacts with me. Sometime I ask him what did the Religion teacher tell you today and he told me that she told him about the prophet called Ibrahim. I asked him to tell me the story that the teacher told him and he said I didn't hear very much because I am sitting on the last chair in the class. I know that he wasn't concentrating. He lies when he said he was in the last, because they sit in groups</p>
49.28	<p><i>Does anything upset him?</i> When you tell him you are very weak in this, he gets very upset and maybe he cries also. Sometimes I don't understand what K** thinks. I hope one day I can understand K**. In the Friends school there was a teacher who supervised K** and accompanied him all the time when he was in KG1. In KG2 there was no teacher accompanying him. He was like the other children. After summer I told him maybe there will be a teacher that is with you in the class. He refused this concept very much and he cries. No my teacher is Nariman the same as all the students. So sometimes I feel that he knows about his weakness and he refuse to accept his weakness. He wants to be the same as his classmates.</p>
51.2	<p><i>Will you tell him about his autism eventually?</i> No. Maybe when he is older. [Accepting change] was a big problem for him when he was younger. He got very nervous and was crying when there was a change of environment. Now everything is very good with him. Wherever we go he is interested and he tries to be happy and play.</p>
52.42	<p><i>Do you feel positive about his future?</i> No, I am not very optimistic. I am afraid because in the Arabic society they still don't know the rights of special needs persons. Now I am working in the justice system I know we are still the low level of human rights. I am not optimistic for K** to live in this society. I tried many times to convince my husband to go out to a country that will ensure the rights for K** and when we will die the people [will] respect him. I don't know about his future. In the school everything is very good. At home when I teach my two kids he is superior in everything. One time I bought a CD for him to learn Arabic. He was 3 ½. The CD, for example, would show a picture of an apple and then it would say apple in Arabic, English, French and Dutch. K** learnt all the languages for all the objects in the CD. I don't have any difficulty to teach him science or maths. In Maths he is very good. In Arabic and English he's not excellent but he is very good. <i>Your main concern seems to be that he should be able to find his place in society.</i> I don't expect him that in Palestine. In Palestine no. Even in Jordan. In Arabic countries I don't feel that K** will find his place. That is why my friend Buran left the country – for her son. (He had more difficulties than K**). She didn't find a school for her kid so he didn't go to school. I need people to encourage me. I am realistic also. I am a Palestinian and I know about Palestine. We have to fight for the rights of [people with disabilities]</p>
57.45	<p><i>Maybe things are changing?</i> I don't think so, no. Maybe after 100 years The school is very good for K**. This is a very positive point in my life. He comes to school, learns, mixes with other kids, wears the uniform. Every two weeks I see his teachers and talk with her about K**. At the beginning of this year she said that K** moves too much and didn't concentrate on his job so I told her to change his group. She changed his group and after this he was much better. He is with a girls called Maryam whom he loves. It is a very great school. The teacher wanted to make the class a good environment for K**.</p>
01/01/51	<p><i>Is there anything you would like the school to do?</i> One small thing. I would like to be in contact daily, but they are very busy and they have many other kids so I cannot ask them to be in contact every day. I would suggest to keep in contact by email, maybe. [I would like to know ] if there is anything to work on at home with K**</p>
01/03/09	<p><i>Relationship with sister?</i> They get on well. Now she feels jealous because we do everything for K**. We talk about him all the time. I try now to be fair with them, not to let her feel jealous of him, because she will take care of him when he is older, so I try to make her love K**, not to feel jealous. All the teachers in the school know about K**</p>
	<p>██████ willing for me to email her with more questions.</p>



## Appendix 8: Transcribed interview – Practitioner – an example

00.29	<p><i>Can you tell me how the autism unit came about?</i></p> <p>Actually the last two or three years we noticed that there was an increase in the number of autistic children in WB and Jerusalem. He had a meeting and we called it a coalition of the Palestinian centres in the WB. We meet together weekly and we make like awareness about autism for parents and for schools.</p> <p>██████?</p> <p>No. Dr J █████, he's in charge of the Medical ? in Ramallah. This is since 3,4 years. We said it's a need for a centre for autism at least in one area and then we go from this place to another area in the WB.</p> <p><i>Is this the first centre for autism in Palestine?</i></p> <p>Yes. The first one. Normally for this. All the centres they don't have money to share in the expense of this programme because it's so expensive. Then our administration make a proposal for the EU to fund this programme and we succeed. They have one thing – they said it should be in Jerusalem not in WB. So we said no problem – we can do it in Jerusalem and we can help all the people in Palestine. We restructured the place, buy all things needed like toys, cupboards, tables, everything. For the group also one year training for the staff before we start. So we did it. We went to Nazareth school for autism four times. Sawa School in Nazareth. We went to London for a short course on the snoezelen room before we buy this and the things is all from England. We went also to Sweden for one week to see how they run programmes for autism there and the strategy that they used with those children. And we took courses – the AAC course and the DIR course. We took some information for psychology ?? like TEACCH – structures and areas and with the structured programme.</p> <p>Then in September we start.... In Jerusalem you have to be licensed to have a class like this because the Jerusalem area is related to the Israeli MoE and MoHealth. So they have to licence the class before we start. We said we are not in an education setting we have a rehabilitation setting – in order to start, otherwise we can't. So we started a s a rehabilitation but we work as education. This class need to be both – health and education at the same time. Also because our children are so small – 3 years is not educational age ???? But they learn every second.</p>
03.50	<p>After we start in September we have ??? from Nazareth. She is a special education teacher she has a PhD .. and she is excellent. She came once a month to monitor our work. If the right way, if we need to change, to have more courses, whatever. So when she came last month she said it's really excellent. Your children progress. Your staff is working on the right track. Keep on this programme. Then the MoE came, the Israeli side and they were amazed and they said now we will give you the licence, so next year will be licence – day care and nursery or kindergarten for autism</p>
06.10	<p>We started with three (children) Also because in Jerusalem they make a committee and decide where this child to go. So they decided for these three to go to Basma School for Autism in Jerusalem. But the family went and they said it's so crowded there we don't want to send our children in a crowded place so we want to be with you. This was a choice for them. Also we don't charge the children. We don't take money from them, only transportation and the family arrange the transportation not us but next year when it's licensed it's our responsibility to take them and send them home and everything.</p>
06.59	<p><i>Will you have more children - Interruption</i></p>
07.34	<p><i>So how long will your funding last from the EU?</i></p> <p>3 years. We start on January 2010 and it will finish at the end of 2012. Then it will be licenced and it will be the responsibility of the MoE (Israeli).</p> <p>The second part of the training grant is to train the staff in the WB and we started this. We select 4 centres that deal with autism - they have autism children but they don't have a setting for education and they mix it with the other children so what we are starting to do is to separate these children to make a setting.... because it is not normal schools: its with multi-handicaps like Downs syndrome, mentally retarded, all kinds of learning disabilities. And this is not good. If it's in the regular school it's ok but with this it's not good, so we talk with these centres to make a class for autism and to restructure it the same way as we have here and we start educating them theory-wise and training ?</p> <p><i>Which are the 4 centres in the WB?</i></p> <p>There is one in Nablus and its not mainly for autism. They have hearing impaired children; they have learning disabilities like Downs syndrome and other mentally retarded children. In Ramallah – Jasmine Society and also they have mentally retarded, autism, Downs syndrome. We have another centre in Jericho also with LD and they have one or two autistic children there. And the 4<sup>th</sup> one in Hebron, with Unwra, the United nations.... Next week we will be there.</p>
10.20	<p>Our team consists of OT, SpTh, Physio Th and the Doctor.</p> <p><i>And how much training do you give them?</i></p> <p>One day a month for each for one year. This is sponsored from the EU. They can't come to us because of the checkpoints so we go to them. We use to do it with the physically disabled for three years because we want to train them to speak the same language with us. Our place in Jerusalem allowed us to have more updated information concerning disability, either physical or intellectual. So what we've learnt we distribute it to the WB</p>
11.20	<p><i>Is it a problem that in the WB they don't seem to have reliable diagnosis, I think?</i></p> <p>Especially with autism. In everything, but more with autism.</p> <p><i>So how do they select the children to go in these units?</i></p> <p>Normally the neurosurgeon and neuro-paediatrician who diagnose these children. Just one, not a team like we've learned. You need to have a full team to diagnose the child. In the WB the only one who did it the neuro-paediatrician ..... and we don't have a system in the WB for the health, the MoH or the MoE who are responsible for these children. There is no system for this so it is individual work. The family took the child to the neuro-paediatrician and he diagnose him and they choose where to go. And sadly to say there is no place suitable for autism in the WB. In Jerusalem, for the Arabs who live in East Jerusalem they have many choices in Jerusalem because they have Israeli ID. That's why the MoH and MoE in Jerusalem are responsible for these children. Not like</p>

	the Palestinian in the WB.
12.56	<i>So if there are Palestinian children living in East Jerusalem with autism, they can go to Israeli ....</i> But it's Arabs... in the Arab part. And also the teachers, the workers, they're all Arabs, all Palestinian, but the sponsor is from the Israeli side.
13.28	<i>How did you select the children to come here?</i> Before you took the licence it's free for you to choose the children and for me I choose not the severely intellectually disabled with autism, I choose in-between – not Aspergers, high functioning and not very severe. So I choose the children in the middle in order to succeed. It's the first chance for us to work with autism and we need to succeed in this. And then later on we'll be more experienced working with them and we can take any. But at the beginning we need to succeed.
14.30	<i>And do you feel you are being successful?</i> With autism it is a challenge to succeed in any area, but with our children downstairs, the three who started from the beginning, they progress a lot. Imagine they came with flapping all the time, screaming, do nothing, even no hand function. In one of them the first day we give him a sandwich – he can't catch it (grasp it) by hand, he just do it by mouth. When we asked the mother she said 'I always feed him'. And he didn't play with hand, he do nothing; that's why there is no hand function what he started. And we didn't introduce PECS from the beginning. We have to settle down the children. Most of the children they have sensory problems – either hypo-responsive or hyper or vestibular ? proprioceptive –all these kind of things. We work to let them down, you know all hyperactive going around all the time. So we start putting our programme and we start with three pictures at the beginning. And then we increase the number. Each time we think that now they know these three, for example in the morning for thinking who's coming to the school, who's not here, and he chooses picture from the wall from the home to the school. And at the end of the day it's the same. So we introduce 'more' and 'finish' – these two things. Then we introduce the basic things like 'I want a drink', 'to eat'. Then we make the setting of breakfast to be choices for the child because it's a learning session also. And even if he give me the wrong one I have to give him what he choose. He has to look and see. And then we add the TV programme, the outside activity, the playground – 15 minutes for each. And then we have individual sessions for the children with the classroom. We have individual sessions every day for speech therapy and occupational therapy. Individually – each child has his own session. The same thing – we use always to choose activities. We have two or three activities and signs – 'finish' and 'more' in the same way. We each use it and the teacher use it. We feel that they progress a lot. They come to the programme and they know what is [happening], what is the next step. And when they will finish, because it will be the [ ]. They know that they will go home at the end. Otherwise they will be so lost. Really it's amazing. People came from outside and they say in two months they progress very well.
18.34	The next step we are preparing pictures, PECS, for the parents to continue with. We didn't do at the beginning because the children not yet ready to use it every situation. But now we are preparing things to give to the mother. Before we have to visit the house to advise when to put the [ ], where to put the pictures, how to use it, how to programme. Our society (?) is difficult. It is not like Europe. Even the normal people they didn't programme themselves, I have to do this now, schedule, we don't have this. It is difficult. So we have to advise how to use PECS in the house, where to put the pictures. The things related to food in the kitchen. The things related to – if they want to go out in the evening – so the picture will be behind the door. We have to see everything at home. We are so busy – me and Iman. Also we have to work here because we are the head of the department here. So I have to work outside of the centre and I have to be there. That's why I choose Rijah (?) and she was with me all the time in the training programme in order to replace me when I am not here otherwise it will not work.
20.24	<i>So how many staff do you have for the autism unit?</i> 4 therapists – two speech, two OT and the teacher and the assistant. <i>Which one was the teacher?</i> The man. The other woman is the assistant. From 10.30 til 12.30 there will be 4: 1 OT, 1 speech and teacher and assistant. So we took each one child for a session and the rest stay with the teacher. And the children know it's now with me or Iman. And we showed them and we change.
	<i>The little girl Hala she was very upset this morning.</i> Hala because she has hypertension [?] and her ability I think is better than the others. So when somebody cries she cries. She's very new, she's just 10 days here. She's settled down and she's working very nice. We had the new one, Mohammed, the other one who's crying, so she's crying with him. But she has the potential to be a good student.
22.05	<i>Do you structure the whole time or do they have unstructured times?</i> They have the free time on the outside. Not every day. We have free play. And sometimes if they come very early because normally they will be together at 8.15, 8.20. So it is scheduled for 8 -8.15 floor time, free time, to put lego and nice things on the floor and they can sit and play on the floor with the teacher.
22.38	<i>What are the main approaches that you find are useful here?</i> Communication-wise, AAC and for the classroom and the OTs it's DIR, this is mainly for occupational therapists. DIR- this is talking about the developmental level of the child: from 0-3, 3-6, 6-9 for example. For this age, for example, there are main aspects that you have to look for. For example, pointing at [ ] and if not this is something. Eye contact from 0-3 with the mother.
24.05	<i>Do you assess the children?</i> Actually we start very soon. Already we started with the last children that we received, Hala and Mohammed and we use the DIR in our assessments. We look for certain things – communication, language, behaviour, play [ ] and you have a sub-description of each. We know that the main problems are communication and interaction. Also they have individual problems – eating, toileting, dressing, brushing teeth – all the things they didn't do for themselves, so mostly they have the same target – to achieve independence and to communicate. And to communicate in all situations of life. And we keep saying to the teacher: you can let them play, they can play, but their programme is to feel with you, to feel that you are here, so you have to create a situation for communication. In each single minute

	<p>you have to create a situation for communication with these children. So all the day we are creating situations for communication, even when they are painting, we have to paint together – I'm here with you.</p> <p><i>So your main approaches are DIR, TEACCH, AAC.</i></p> <p>When we went to Sweden they introduced us to ABA. They use more PECS and ABA. <b>We find that in our country ABA is so strict. I feel like it's more emphasis on autism. It feels like robot. And this is not communication. So we mix the things we find from everywhere.</b> So we use PECS but with AAC, not just PECS but with sign language, maybe with [ ] – you record your voice even if the child didn't talk, you record 'yes', 'me' so he press and he'll recognise the voice and, by the time, he will say it by himself. So if I say 'who want this?' 'Anna'. So we emphasise talking, sign language and PECS at the same time.</p>
27.48	<p><i>Are any of them on medication?</i></p> <p>Most of them they don't have. No one have any. The people who came from WB they come at not early age, they come at 6, 7 and they didn't be in a school or any setting or treatment so they took medication because all the time hyperactive and the families didn't know what to do so they go to the neuro-paediatrician and they give them Ritalin, most of them.</p>
28.30	<p><i>How long will they be able to stay with you in the Unit?</i></p> <p>It depends. Now we are taking them so if they progress to be another class, if we have more children, so we use the ..... I didn't show you the therapist room. So we'll use these rooms for classes and the therapy will be here, speech therapy and occupational therapy in the centre if we feel we need to change. If not they will stay 2 or 3 years in the same class. And if we see that one of the children could be in a regular .. we'll send him to the Kindergarten. Because we have Kindergarten her and it is pro-inclusion. We have CP children in the Kindergarten, we have slow learners as well. It's a regular school included with special needs. We have more than 90 children with different aspects of disability. [Will look for opportunities to include them] And the family likes that. That's why they brought their children here – because they have the chance to be with regular students.</p>
Interruption – new recording	
00.10	<p><i>The future- you are optimistic that some of the children will be able to go to regular school.</i></p> <p>Some of them, I am not sure. Hala. When she's quiet she works very hard. She's very good. She has sensory overload and at the same time she doesn't like somebody crying. Mohammed since the morning crying. So this is a good sign actually with Hala because if she feels that somebody crying [ she's aware of somebody else]</p> <p><i>Will you have any more in that class?</i></p> <p>If the class is licenced we should have 8 but I will try to keep it just 6 children or it will be too much. 3 years old and all diverse. It will be difficult to have more. I will argue with the people who are responsible</p> <p><i>When you're licenced will you be able to choose the children?</i></p> <p>We keep ours because they all from Jerusalem. They all related to the MoE and the Ministry of Welfare and we have this cooperation between the 2 ministries.</p> <p>[In the future the new children will be] sent to us. Like the other school, Basma – it's the same name as our centre, they sent to them the children and it will be the same for us they will send the children to us.</p>
02.49	<p><i>So the other Basma centre is nothing to do with you?</i></p> <p>Different school but for autism and for different ages. They have a lot of children. It is for the Jerusalem area and it's a school related to the MoE for Israel.</p> <p><i>These children if they couldn't go to the mainstream school?</i></p> <p>If they couldn't go then they will have another setting when they are older. Maybe they will transfer to Basma school where they have older children- 12,14,16. Basma school is only for autism</p>
04.03	<p><i>So how do you see this? Education? Rehabilitation?</i></p> <p>Because we have intensive therapy every day. Not like other schools. At Basma school they just took the child once a week- for OT and for speech. Also [ ] school is the same – they don't take the children every day for sessions. [in the long run our aim is to educate schools].</p> <p><i>Started at the Jasmin Centre in Ramallah.</i></p> <p>I Nablus, actually, they are very cooperative. When we said that the classroom needed to be changed and the structure of the room to be more safe for the children, they are willing to do whatever we say to them.</p> <p><i>Are they able to come and visit here.</i></p> <p>It is not easy because of their WB ID. Otherwise they have to pretend they have a note from a doctor to come here. Parents: they come very often and they stay the whole day. But the thing is when the child see the mother he keep catching her and he won't work. That's why we make it like this: stay 1 hour and then watch from the window. Also to give the feeling to the mother that her child is secure and safe. Because, especially with autism, they are so afraid. You know this child can't talk and can't deal with people. They are willing [to learn the strategies] they keep asking.</p>
06.45	<p><i>Attitudes towards SN and autism in Palestine</i></p> <p>In Palestinian society for PD now no problem because through the two intifadas we have many injuries – spinal ? and so on, so it's like a hero. And this has related positively to the other special needs people. So no problem. They will go and they have more access for helping them than for intellectual disability and autism. PD – no problem - they looking now for adaptation to the environment for them – streets, buildings. Now they are more accepted than before. But with intellectual disability and with autism til now there is no enough awareness, especially about autism. Some of the people are dealing with them as mentally retarded. [ ] when you go to the restaurant with your child with autism others are looking at the mother like she didn't know how to raise her child. One of the mothers from the WB told me 'I didn't go anywhere with my child, even to my family, because he is so hyperactive and making troubles so she prefer to stay at home. If I put myself on her chair I would do the same. Because those children need to go every day to the school – at least to stay 6 hours. She will do what she needs to do and he will be in a setting. But no place for treatment or for schooling – every day with her- it's a disaster.</p>
09.50	<p><i>Stories in WB about children being hidden away...</i></p> <p>Or tied because he is so hyperactive and destroy everything in the house. It's like a dog, yes. I've been working in the field since 1991 and this is the most difficult. You took their problems home with you. Sometimes when I am</p>

	<p>praying I pray god will help me to help them. Give me a way to help more. Sometimes I feel upset when ... you know children with autism not always the same. Sometimes they come and they are very upset – crying. You don't know what's gone wrong – maybe they are feeling sick, maybe something at home. You don't know. So you feel so upset. What can I do with them?</p> <p>When they start using the cards and do it by means, we are celebrating. It's like when your child walk the first step. It is like your child. They touch your heart. I work with different disabilities but those children they touch your heart, I don't know why.</p>
11.55	<p><i>Staff understanding</i></p> <p>In the beginning because they don't have any experience when we started in September they were so upset. The children crying. They didn't know what to do so at the beginning they think to leave. But we support each other. We said look, you have to be patient. You're new but you'll see. You will love it and you will miss those children. Now if you ask them you'll see the difference. They took the courses that we took and I am with them all the time and we talk together always. The first two months I was so strict with them and now we work together.</p>
12.57	<p><i>The teachers in the school</i></p> <p>We have worked a little with the teachers in the kindergarten and we brought them to work one day, two days with the autism [unit]. But with the school we don't have this age now. Also you need time and money for this.</p> <p><i>Possible undiagnosed children in the school</i></p> <p>We have one on the school. I brought him here with [ ] and he's Asperger / high functioning and you can see. The family refused. The headmaster said don't work with him because the family refused. They said my child is normal. You talk with him and he answers something else. Sometimes you ask a question and he didn't understand and he repeat the thing you said.</p>
12.43	<p><i>Adults with autism</i></p> <p>In East Jerusalem they have a place to go to. Vocational ..... I think there is a home for them and special staff dealing with them. In WB if you have someone with HF autism nobody considers him as having autism.</p> <p>I will tell you a story. My son is 10 years old and he has in his classroom an autistic child high functioning. So before I explain to him he keep saying to me, mother there's a child and he's also a relative to the headmaster. My son is in a private school otherwise he will not be in a regular school. So he says he's always shouting, he's always interrupting me while I'm writing. So I went to school to see who is this child. The minute I saw his face I know he is autistic. You know they look like plain face, no facial expression and the minute you talk to them you can understand so I explain to my son that he has problem and now he loves him.</p>
17.32	<p><i>What are your hopes for the future?</i></p> <p>I hope we can cover the whole area – WB. I wish the MoE and MoH in the WB would consider this as a big issue. There is a group of people they need a lot of help – even more that the prisoners. Because you can't imagine the suffering of parents. It is a human rights issue. It is a group of people who need a lot of time. In my opinion, more than the poor people who can't find food. The mother with the autistic child if you give her the choice to find a setting for him or to eat, she will have the first choice.</p> <p>We talk with the parents. They start making parents' committee in Ramallah and the whole area. We talked with them to push the MoE and MoH for at least one classroom in each city. They hope. But it cost money and it is not easy.</p> <p><i>Do any health professionals in the WB have training in autism? No</i></p> <p>[the teachers] don't know what autism is.</p> <p><i>Friends school – some knowledge</i></p> <p>You chose a school for the rich children, and maybe some of the teachers know something. But if you go to the government schools it's terrible.</p> <p><i>I wanted to work with a govt school.</i></p> <p>It's better than Friends – it's just for high class people. This is not our society. It is children of doctors, lawyers, engineers –for the people who have money.</p> <p>Here we believe in equal opportunities for children. Not [privilege] for those who can pay and the poor people not. We believe in equal opportunities for children everywhere and without any discrimination – race, religion whatever. If you make a research about the Palestinian society it is not the true situation.</p> <p>Like in England or the US, the rich people they have different opportunity.</p>
23.45	<p><i>The idea is that they (Friends) will cascade their knowledge to others</i></p> <p>Are they willing to do this?</p> <p>My husband is a refugee. We live near the camp, not inside. There are a lot of autistic children there and no setting for them.</p> <p>We live in a country where we have a problem every single minute – not just autism, not just poor. The occupation is a big challenge for us. If there is no checkpoints between Jerusalem and the WB it would be easy for the people to come here, easy for us to transfer children.</p> <p><i>Goodness knows what it is like for the children with autism in Gaza</i></p> <p>That's why even if you do something you feel it is nothing until you feel that everybody has the chance to ....[]</p> <p><i>I take my hat off to you.</i></p>

## Appendix 9: Example of theme grouping - Teacher

### S\*\*\*\*\*: Key Themes and quotes

Theme	code	Quotes / Comments
Our school-policies and practice	A	Many details
SEN Practice in Palestine	B	Many details many schools, do not accept children, under the reason that they are not able to provide any educational help for that child because that child's needs are above the capacity of the school. So on that basis many children are not accepted, [saying] our school is not able to address the needs of those children.
Diagnosis / identification (incl medication)	C	I have not until now received a formal diagnosis in the West Bank from a reliable source. I say this with full confidence I have not until now received a formal diagnosis in the West Bank from a reliable source. I say this with full confidence We no longer have access (to centre in Jerusalem). After the intifada it was really difficult for that. (In any case) they have a very medicalised approach. They once gave a diagnosis to one of our children and it was really very destructive. Often there is a lot of confusion... and they are diagnosed as ADHD and they put them on Ritalin rather than realising that there is a problem with communication or social interaction.
Autism practice (incl skills and knowledge)	D	One of the main obstacles I faced was that I had nobody to refer to, nobody to discuss with and share my experience at school Even the most supportive teachers at sometimes [might say] 'my god, he's so spoilt'. Now, there is a lot of interest in autism in Palestine. I feel that they (MoE) are a bit hesitant, frightened let's say. They are not. I don't think they actually believe that a child on the autistic spectrum can be part of a school. I'm 100% sure that there are children on the autistic spectrum in government schools. And sometimes the teachers, or even the so-called specialists, are not even aware that they are within the autistic spectrum. (they are treated as) Naughty children, ADHD or intellectually challenged, or developmental delay, or speech and language.
Social attitudes and perceptions towards autism and difference	E	we still don't have a very positive perspective. People in our community look at it in ...pity, pity you know. It's something more from the religious, charitable perspective you know... poor parents. social stigma related to autism in general is not very positive and it is really hard for the parents, very hard for people to understand what it means. They really relate it more to a mental issue. Sometimes they're even afraid to talk about it. Autism, there is an awareness nowadays in the media. It is talked a lot about. It's more common. It's [now seen that it is] not the parents fault. There is general awareness in the Arab media as well. Nowadays with the satellite you get all channels so people are interested.
Inclusion issues	F	Inclusion means for me the way you teach. In Palestine we have a big big problem. Most of our children who have needs don't even have education possibilities to be part of a school. the main ideas of teachers and parents is that we need more centres, we need more special schools I don't only believe in educational inclusion. I believe also children have to be in school for social inclusion for their growth as a whole. And this cannot be provided by special schools. It's very strange and funny in the sense that they are talking about inclusion and at the same time they are doing an integrated classic system. So the children with sen go into these resource rooms and it is only for 1 <sup>st</sup> , 2 <sup>nd</sup> and 3 <sup>rd</sup> graders. So those children attend those classes and I think they have recently extended it for the 4 <sup>th</sup> grade in some schools only. So they attend this class ... basically they work on literacy and numeracy as well as certain skills. So it is not exactly an inclusive set-up and there's not a lot of work and partnership with the regular classroom teachers. The regular teachers prefer to send the children who are giving them trouble or who are not doing well to the resource room.
Parents and families	G	When he couldn't draw or write she would become very tense, she would even threaten him with the slipper. I am approached by tens and tens of people every year asking me desperately, 'Salma help us, we only have you and god'. parents are isolated, they don't have the support. Parents' voices are being more and more heard and they are really seeking help.
Barriers to progress	H	The teachers come from educational institutions with no training at all, not only in dealing with children with sen, but in education in general sometimes. When I ask this question from the Ministry or from teachers they tell me, well we have overcrowded

		classes, we don't have the skills and the expertise, we lack the resources
		Another big problem on top of everything the is pedagogy of education we have, it is very traditional [and] didactic. Our system of education is very very rigid and this in itself is a big obstacle towards inclusion. If I want to include a child on the autistic spectrum I need a lot of flexibility. I need a classroom that allows for different methodologies of teaching.
		the whole system is the obstacle.
<b>Opportunities and aspirations</b>	I	Personally I believe it's working on attitudes. But how can you change attitudes? This can only take place if you give people the skills and the confidence and the training.
		So it really needs I believe we need to change attitudes and we do this by giving the teachers extra skills, training the teachers, giving learning support assistants have to work in partnership otherwise we have another form of exclusion. It is too easy for the teacher to do it her own way if she has a learning support assistant who just works with that child.
		changing the classroom environment.
		I believe if any model becomes successful then this can be helpful to reflect to other schools a



## Appendix 10: Introductory Questionnaire - Collated responses (MoE workshop)

Q1. Things I know about the autism spectrum	Resp.
Disorder of the nervous system which causes loneliness and the person can't recognize what is happening around. He/she can't feel the happiness, or sadness	1
It's a mental disorder, affects the central area in the brain. Also, it affects the child's behaviour and attitudes.	2
A disorder of the nervous system, affects negatively in recognizing what is happening around.	3
Loss the ability of communication. Loneliness	4
Emotional illness. The person can't make any kind of communication with the people around, the causes are not known yet. There are a lot of kinds, simple and complicated.	5
Psychological disease affects the children, may appear at the birth stage May be hereditary. Affects males more than females	6
A disorder, the person can't communicate with others "verbally, auditory" he has his own world; his body language is not understandable from others. Each autistic condition is different than the other.	7
Loneliness. Repetition of certain movements. Can't communicate. Can't recognize the things around.	8
The person can't communicate with others. Can't communicate verbally. He is lonely	9
There are psychological and behaviour symptoms affect the child communication with others.	10
Emotional disorder, the person can't communicate with others. Also, it is a nervous disorder, the person moves a lot, make strange noises	11
Disorder affects the children since the birth till 3 years, it causes: Problems in social communication, Visual communication, Activities and interests	12
Loss the ability to communicate with others	13
Children with special needs, are living in their own world	14
Psychological disease affects the children since early ages, and affects the social, emotional behaviour aspects.	15
A disease affects the child's nerves or the electrical waves in the body which cause a brain dysfunction	16
A disorder that affects the child's communication with people. It is a huge spectrum	17
A disorder appears from the first till the 4 <sup>th</sup> year. Affects males more than females It affects the person communication, skills, play and the senses	18
The person separates himself from the world. Did not specify if it is a disease or disability. Affects males more than females. It affects the person pronunciation	19
Psychological illness affects the children at the age of two. A lot of cases are from twins. Symptoms like: setting alone, like his own games, do certain activities and movements, like routine, sometime hits himself	20
Symptoms like: setting alone, live in their own world, do not make eye contact, do certain activities and movements. Disorder affects the children from 0-3 years, a lot of kinds Some autistic people are gifted	21
Social, behaviour disorder. Affects males more than females. There are 3 levels: simple, middle and complicated	22
It appears at the age of 3. The symptoms are: Introverted, certain movements, delay in speech and difficulties in eye contact and focus	23
Disorder affects the communication with others. The children do certain activities like shaking foot	24
Behavioural disorder since the birth.	25
Loss the ability to communicate. Behavioural disorder	26
Mental disease affects their ability in doing activities and tasks. Cause problems in social communicating	27
Maybe it is a mental disease, makes the child feel alone.	28
Loss the ability to communicate and to speak.	29
Disorder affects the ability of communicate with others	30

A kind of disability no one knows the real reason, maybe there are some genetic reason or maybe because of some kind of foods.	31
It is a developmental disorder affects the nerves; it causes loss the communication, academic skills, speech.	32
It is a complicated disorder in the brain function. It affects the communication with others.	33
There is a difficulty in including them in schools. Problems in focusing and attention	34
It is a syndrome, its rate 1/1000. The child can't communicate with others and live in his own world	35
Imbalance in the brain cells which affects the psychological, behavioural, mental and social function and that affects the person's life in all the fields	36
<b>Q2. Things I know about supporting a child on the autism spectrum</b>	<b>Resp</b>
How to treat and rehabilitate them.	1
No response	2
No response	3
He needs special programs.	4
To include a child with autism in a normal class is a hard thing except for the simple kind.	5
We can change the child's behaviour, and then the child can depends on himself in the life	6
I can't give help to autistic children, and I would like to know how. Also, I am working hard to accept the autistic children in our society, and to support them.	7
Adapt the daily life. Teach them the daily life skills. Communicate with others	8
There is no supporting for them especially in the governmental schools	9
No response	10
Inclusive as a kind of supporting. Inclusive educational programme which is a kind of support and awareness	11
I am working now with governmental schools to support autistic children	12
Teach through education. Take the children into tours and picnics	13
These children need special education and to use special techniques.	14
The autistic children need special rehabilitation programs	15
The child need support and help according to the condition and case. Give a treatment by some medicine.	16
Offer the child a comfortable place. Praise them. Teach them by pictures and drawing	17
There are a lot of programs can help like TEACH and PECS	18
Early intervention. There are a lot of programs which can help like PECS	19
They need psychological, social and academic rehabilitation form specialists	20
Organise the place and do not change it, because the child like routine	21
No response	22
Offer help like speech therapy, occupational therapy. Include these cases into schools	23
How to communicate with them	24
Make a treatment plan for each student with many specialists like: speech therapy, educational therapy... etc	25
Needs different specialist to help	26
Offer special education programs. The autistic children like routine	27
establish some foundation to help them.	28
Offer a special rehabilitation programme	29
We must know their needs and how to have their trust.	30
We must deal with the association that are working with the autistic children.	31
Teach children through some programs like Pecs, Teach and behaviour modification.	32
Must make early diagnose and early intervention in order to offer help.	33
Employ the music in teaching the children. Depend on the medical report to diagnose	34

The autistic people need special programme rehabilitation.	35
Support the person, the family. Offer them a good education	36
<b>Q3. Things I would like to know</b>	<b>Resp</b>
The causes. The symptoms. How to diagnose. How to deal with autistic children	1
How to diagnose. How to deal with them	2
How to deal with children. How to diagnose. What are the causes	3
No response	4
How to deal with autistic children. How to include them.	5
How to support them. How to diagnose them	6
Symptoms. How to deal with them. How we can work with autistic children and make a progress.	7
How to deal. Communication skills	8
Educational programs for them. How to evaluate them. How to evaluate their skills and abilities	9
I would like to know the symptoms	10
To know the autism types	11
Practical training inside special centres that working with these people	12
How to diagnose and deal with them	13
Their characteristics. Tools and techniques which could help in teaching them	14
How to work with autistic children	15
How to treat the children? The causes and the kinds	16
How to diagnose them	17
Some educational programs. How to diagnose the cases	18
How to diagnose the cases	19
What are the centres that can help or the people?	20
How to diagnose? What are the different kinds?	21
If there is a possibility to include the children in the schools	22
How to decrease their movements when these movements could hurt them	23
How to develop their speech skills	24
The early intervention and how to include them in the schools	25
The causes. How to diagnose? How to teach them?	26
How to diagnose the children, and support their teachers?	27
How to deal with them and have their trust?	28
How to deal with them? How to diagnose? How to treat them?	29
How to deal with them?	30
How to diagnose and treat them?	31
If there is a treatment whether by medicine or special programs	32
The causes? How to diagnose? Techniques and ways which could support autistic children	33
How to diagnose them?	34
How to help these people? How to diagnose?	35
The model definition for autism. How to treat them psychotherapy and medically. How to deal with them at schools	36

## **Appendix 11: Focus group 1 and 2 - Transcriptions of group feedback (MOE workshop March 2012)**

### **Group discussion 1** (S\*\*\* translating in situ)

**Autism in Palestine: Do you know of any children with a diagnosis of autism?  
How are they educated?**

#### **Group 1 (I■■■)**

■■■■. I am an IEC, Head of the Society for the Friends of Autism Society, also a volunteer for several..... I will talk about two cases in public schools in Ramallah. We had four cases that were included in one school. Some of them left the school because the school and the teachers were not able to deal with them. We have one student now in Faisal Hussein School – this girl was included from first grade. She has a formal diagnosis from a neurologist in Palestine and she has another diagnosis from Jordan. This girl is in 5<sup>th</sup> grade now. She benefitted from the resource room and she is still included and she is doing very well. At the beginning it was very difficult. We suffered. She had a problem with the teachers and now everything is very good. Now the teachers don't even say we have a student with autism. And all her classmates cooperate with her. It's a very normal situation. She benefits from the regular classroom. The regular classroom teachers also help her. So it's not only the resource room teachers who help her. For us, this is a success that a regular teacher is working with the child. It is also a success for the society of parents because it shows that it is possible to include a girl (with autism). We had another case who stayed until 5<sup>th</sup> grade but then he left because his parents migrated out of the country. We have another student in secondary school who stayed until 6<sup>th</sup> grade. She is now a student who comes to Society for Parents. She does embroidery and a lot of handicrafts. There is another student – I am telling you this because I want you to know that there are students on the autism spectrum in schools. We have students who are included in our schools. How can they be included in schools? It is very important that they have programmes of communication. It is true we use with them the visual programmes. We use pictures so that kids identify concepts and words through the pictures and then .... the word itself. We have also a behaviour modification programme. A psychologist, a specialist, is the one who designs this programme. We use TEACCH which covers all the skills: cognitive, language. [There are] elementary teachers and psychologists who are able to work with children on the autistic spectrum. We also have speech therapy. So these are the things that the society offers. Functional .... so they don't talk. But it's not a matter of an inability to talk. It's a functional disability so we work with the kids with the speech therapists. We hope that there are more specialisations.

Interruption...The first girl you said she was diagnosed in Jordan. Did this girl get a diagnosis from Palestine. Is there a diagnosis in Palestine?

We have indicators and then we do an interview with parents. And we do a case study for the child. So there is no formal diagnosis but.... and then we start working with the child. We don't have any specialities. We need more of team to do that.

#### **Group 2**

I work in Hebron. I have seen only one case and that was diagnosed from Jordan and from Amira Basma. He has a diagnosis of autism and the parents brought him to us because he is 6 years old and they want to put him in a school. The pre-school could not work with him: he was so aggressive. He was not responding at all to them and the parents approached the Ministry of Education and they wanted to know what to do with him because they as parents found it difficult. (She is in a centre – she is not an IEC) We have to first of all make an ability test. And then we work on a plan to improve those abilities. We send him to a psychological centre and they told us that yes the child has autism

and it is a severe case. He is very aggressive. He does not respond to the parents' instructions. He has very simple words. He has moods. He doesn't like to break his routines. He sits under the table and watches TV every day. Who does he learn from? He only learns from himself. At our school we found it difficult for him to be part of the school .... We have occupational therapy, we have speech therapy, we really want to make sure that this child can benefit from all the services that are provided. He only can classify colours. His speech is very poor. There is not a single institution that can help him ..... and we don't have any diagnosis in Palestine ..... we had the diagnosis from Amira Basma and from Jordan. We are dealing with him on a behavioural level but not as an autistic child. We sent him to the speech therapy because we need to help him to communicate because when he wants to communicate he bangs his head on the wall. We tried to find a centre that could address his needs but we could not find a single centre. We could not force the school to take him because there is no single person at the school that is able to cope with him. [Does he take medication?] Yes. The mother stopped giving him the medication.

### **Group 3 (M██████)**

I am from the Resource Centre in Ramallah. I want to talk about one case I worked with individually. I started in 2007, training parents and teachers. This child came and he was diagnosed with adhd and I worked with him. He had a problem with self help skills and academic aspects and he has hyperactivity as well. This boy had very good communication. The mother was always seeking for treatment for the child. He was 3<sup>rd</sup> grade when he started to have problems in his education. Academically and socially there were a lot of problems appearing at 3<sup>rd</sup> grade. The mother said one day he had a very high fever and it may have been a form of meningitis. There was some form of damage but it was not clear. But as the boy grew he started losing the language. He started having repetition and repetition in his behaviour, like mannerisms, facial gesture and saying 'I want to go to America' (repeatedly). It started with repetitions and then obsessions on certain issues. There was a kind of deterioration in his situation. There was no improvement. He was taking medication for the adhd. The parents are educated and they really care about this case. They took him to the United States. He saw a specialist there but there was no final diagnosis. Recently another specialist has seen him and the last, recent diagnosis is that this boy is autistic. The mother didn't believe what this doctor said. She said 'OK he's autistic but he can communicate'. He has hyper activity but she wasn't convinced. And at the end we have to work with that child. It was more on life skill goals – time, place and also social activities outside, transportation, how to go to a restaurant, how to deal with money. Recently he has enrolled in an institution centre for children with intellectual disabilities. He went to China [for stem cell treatment]. We saw deterioration.. he lost the language. He cannot use language any more. Before the operation he used to memorise songs such as from Fayrouz but after the operation he lost the language. The parents did other research and then they discovered the diet – gluten -free - now they are trying the diet. He actually gained weight – 5 kilos in a month and a half.

### **Group 4**

We are talking about a child who was diagnosed with suspected autism. There is always a question as there is no definite diagnosis, it is always 'suspected'. We have psychologists and psychiatrists but they are not really qualified to give a final diagnosis. I was introduced to the child ... His mother tried to put him in schools. And the question was 'No there is a problem in including that boy at school'. There is no single specialised centre, there is no standardised test. There are speech therapists and people in Special Ed.... they tried to help. The last 6 months he is at a day care centre – now he has started going and they will put them on life skills, pre-reading skills. He always has circulation and he always has body tics. He is a very closed child. To protect and stimulate that child was very difficult for us to do. These attempts are only patching. We really need special centres that can ..... rehabilitate autistic children. It is not therapy. It is rehabilitation – it is a long-term issue

### **Group 5 (N [REDACTED])**

I want to talk about two things. One is that we have special education centres in Bethlehem that had children with autism disorders. My masters degree was in using Drama in helping and building skills in children with autism in social interaction. As you all said, most of the centres in Palestine when I started working, there were no specialised centres for this category of students. Even if I wanted to collect information I couldn't. They would come and talk about children but they didn't have any specific evaluation or diagnosis for children within the autistic spectrum. So I used children who went to Jordan to be diagnosed to be part of my study. The children in Palestine are not diagnosed so they could not be included in my research.

I am now working with a child who was included in the first grade. He is 8 years old. We included him at the beginning of this year in 1<sup>st</sup> grade. This child was never included in any educational set-up either in school or education. All the pre-schools refused him. The schools were very far away and there was a lack of awareness. The parents went to the minister of education and wanted to register the child. They brought the diagnosis reports. This boy was also diagnosed in Jordan. A checklist we did complemented the diagnosis from Jordan. Before including him in 1<sup>st</sup> grade we visited the school that was close to his house and we prepared the school to include that child in the school. We worked with the teachers and particularly the first grade teachers. We clarified what are the procedures to be taken. The condition was that the mother had to be in school. I insisted that there had to be somebody to support him. It could have been anybody. And so the mother was attending with her child in the class. She attended for 2 weeks, daily. After 2 weeks they all registered their reports and we had a meeting with the teachers, the administration, and the parents to discuss what were the obstacles, what were the positive [ ] and what are the behaviours that are taking place in the class? So we decided to include him partially – 3 classes in the day. He would come every morning. He would come to the queue. He would line up every day. I am not now working on his academic development, I am working on his social interaction skills. The emphasis was on that and it was clear to the teachers that it was organised with the emphasis on that. So they gave the reports and the mother also reported that there has been interaction. So we continued the 2<sup>nd</sup> semester with him, based on the positive aspects. I am very happy that the mother thanked her very much for putting my son in this school, although it is a lot of effort on her part to come every day. But she really cares of giving support. Now there will be a workshop for the whole school so that the whole school will know how to work with that child.

### **Group discussion 2**

**Are there any barriers to the inclusion of children with autism in schools in Palestine? If so, what are they?**

#### **Group 1**

As a group we took autism as though it is one of the disabilities generally speaking what sort of barriers they face in Palestine. Now we have the possibility of including all disabilities in our schools. For our team it's a new area. We need more training and awareness on autism. In the field they need more programmes for the intellectual disabilities. We have barriers in teaching generally for all kids, not only for autistic spectrum. Briefly, the barrier is not in inclusion, it is in how to include as in rehabilitation, teacher training, more teachers working in the field of special education. We have two parents who we reject and deny [because their children] are difficult to work with. Then we have other parents who feel it is a problem. They are aware of it but they feel it is an internal problem. Policies and evaluation / assessment. Other institutions have to be involved – maybe the Ministry of Health, Ministry of Social Affairs.

#### **Group 2**

Maybe the points will be repeated because they were already mentioned. 1<sup>st</sup> point: there is no assessment / evaluation; no assessment tools, behavioural tools. We need a team to diagnose and assess – OT, doctor, neurologist, paediatrician, speech therapist, special ed educator. The school environment is not suitable; lack of resources and educational material. They need training: teachers, supervisors and counsellors – they all need more training. We don't have any special programmes like

TEACCH, like visual aids. We need to have them in Palestine. Also, there might be some negative attitudes, unacceptance, sometimes from the administrators, from the teachers and even from the students. The financial situation of the families is usually very limited and they need a lot of support. And there is a problem also from the policy makers, whether it is the MoE or the Ministry of Health and there are no special centres for autism and even the ones that exist need to be developed.

### **Group 3**

We, the group, worked on two levels: on the level of the school and on the level of the society. The physical environment of the schools are not prepared for the schools. Kids on the autistic spectrum can sometimes have an aggressive kind of behaviour - banging their heads on the wall and they might hurt themselves and the schools can't adapt. But this does not mean that they cannot be included. What we are trying to say these areas and lack of specialists to diagnose and this is not only at the level of the MoE. Now we have Resource Centres but we don't have people who diagnose [Interjection from Mohammed: Yes, we don't diagnose but we can talk about the characteristics. We can assess indicators but we can't say that this child is on the autism spectrum]. The MoE may be contributing but they are not interested in autism. That is why the MoE needs to train people who are working in the field, to train them in autism. We see that there are many scholarships for teacher training abroad but we have not see a single scholarship given by the MoE to anybody treating [inaudible because of uproar ? Dealing with autism?]. On the level of the society – society is negative and rejects children with autism. The Ministry of Health says 'this is not a disease and therefore it is not our responsibility'. They go to the Social Affairs and they say 'this is very costly'. On every level, they throw it on the other. We also believe that the Bureau of Statistics is responsible because there is no census on how many there are on the autism spectrum. The media is not giving enough attention towards raising awareness. The media should work on making it more positive and changing attitudes. Parents are not putting enough pressure, they have a problem. They are not very serious in gaining their demands. There has to be a lobby to put pressure, to advocate for the needs of their children. [Interjection 1: they are not even mentioned in any law. Interjection 2: We need to help the parents make a lobby so that they make a demand for the rights of the children so that their needs are addressed] Also, financially, it is very costly for the parents. [Another issue] Teachers salaries are very low so that it is seen more like a voluntary job.

### **Group 4**

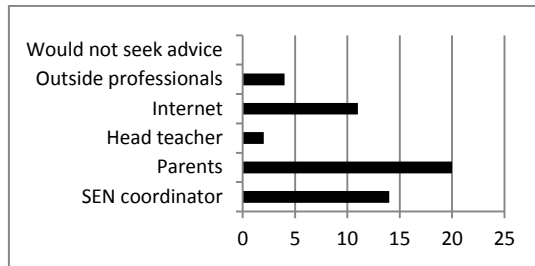
There are problems in diagnosis – it doesn't exist. The neurologist, the psychologist, we need a team of diagnosticians. There is no clear policy and approach from the MoE in dealing with kids on the autistic spectrum. Children of the autistic spectrum do not receive any behaviour modification or any other kind of intervention prior to their inclusion into the schools. There is a lack of information and awareness with the teachers on how to deal with children on the autistic spectrum. There is a lack of specialised centres and how to deal [] and they don't give right evaluation and this causes a lot of confusion. There are no specialised resources as well. The school environment, the classroom environment is not prepared for the children. Lack of awareness programmes in schools about children on the autistic spectrum.

### **Group 5**

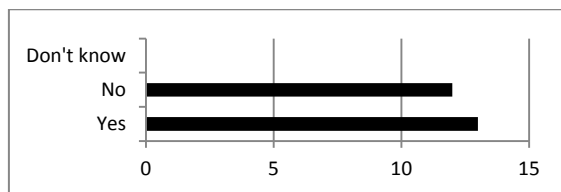
The points that he is going to talk about are more or less the same as has been said by other groups. I am usually an optimistic person. I am not saying we don't have specialised people. We do have them, but we have limited numbers. Why do we have an inferiority complex. We have a problem: we need training. The positive point that you should know is that the MoE doesn't approach and real words with children on the spectrum.??? We are talking as we did from the beginning or the workshop. Our role is to work with the indicators. We go to the school whether this child has autism or not or they have any intellectual disability. They might have some behavioural characteristics that are similar to the autistic but we work with those children. We work on their needs and we try to include them in the school environment. If we look at the general policy of the school it is the EFA (education for all) and we are all working towards this policy (uproar). Listen to me. Maybe the percentage of autistic children is lower than it is in the UK. We go to school, to the Resource Centre, every day and we observe. We need awareness sessions for the teachers.

## Appendix 12: FGS staff questionnaire – presentation of data

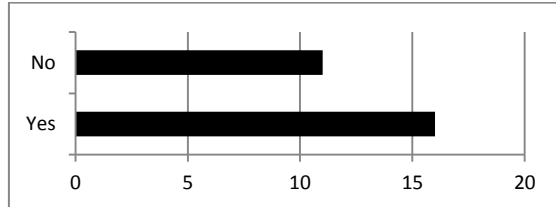
Q1 Where might you go for advice in understanding the needs of a pupil in your class with special educational needs?



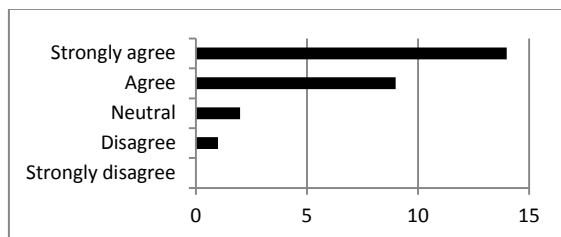
Q2 Do any of the children with whom you work have a diagnosis of an autism spectrum disorder?



Q3 Have you had the opportunity to learn about autism?

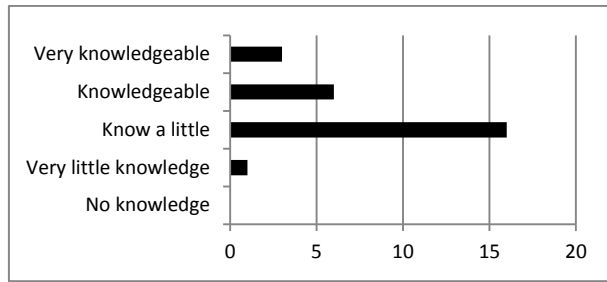


Q4 Children with autism should be included and taught alongside their typically developing peers.

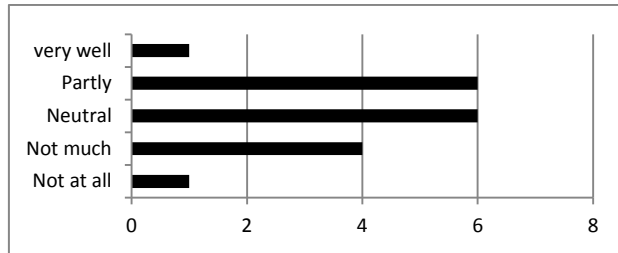


Q5 In my understanding about the autism spectrum I feel that I am:

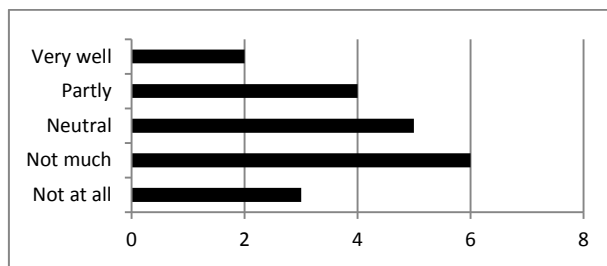




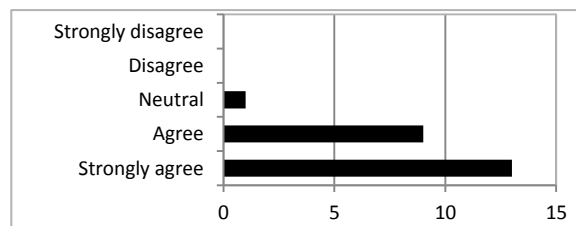
Q6 To what extent has your training prepared you for meeting the needs of the average child you work with?



Q7 To what extent has your training prepared you for working with children on the autism spectrum?

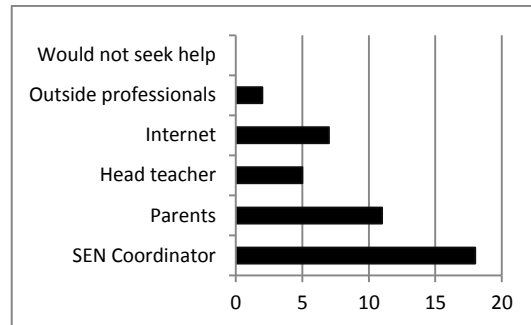


Q8 I would like the opportunity to develop my skills and knowledge for working with children on the autism spectrum

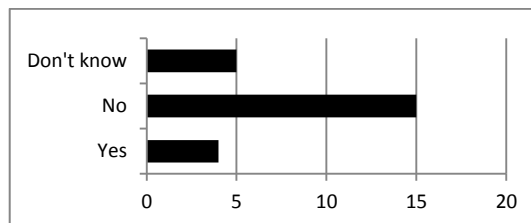


## Appendix 13: ABC staff questionnaire – presentation of data

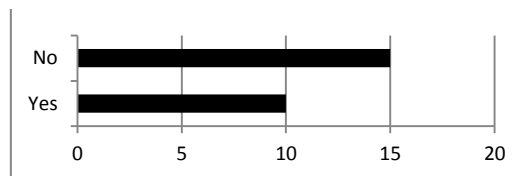
**Q1 Where might you go for advice in understanding the needs of a pupil in your class with special educational needs?**



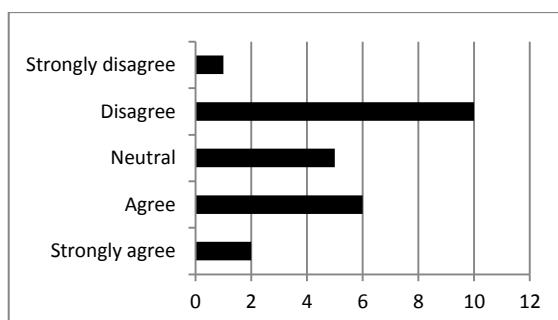
**Q2 Do any of the children with whom you work have a diagnosis of an autism spectrum disorder?**



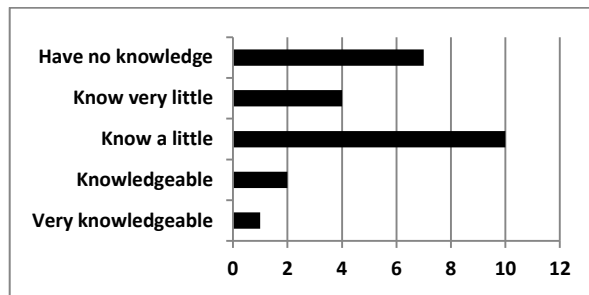
**Q3 Have you had the opportunity to learn about autism?**



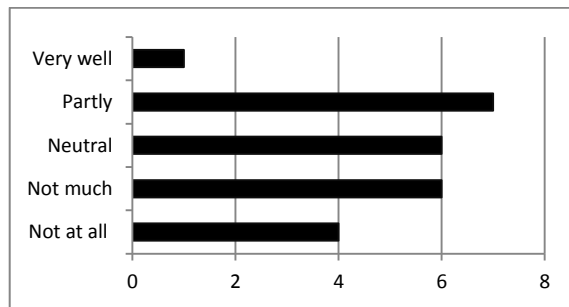
**Q4 Children with autism should be included and taught alongside their typically developing peers.**



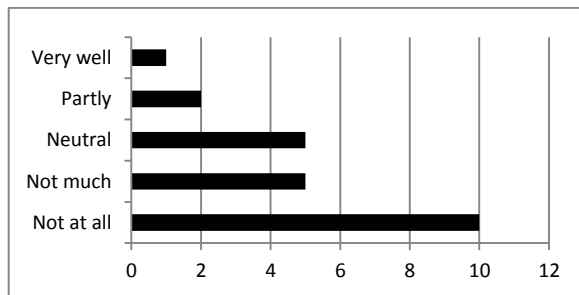
**Q5 In my understanding about the autism spectrum I feel that I:**



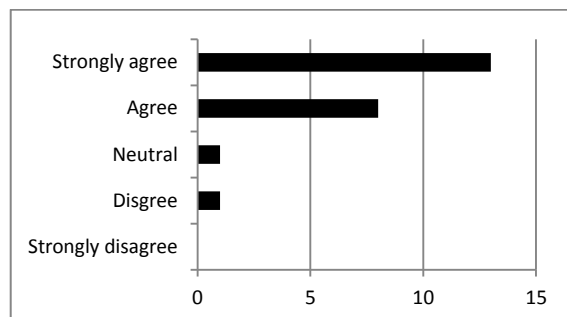
**Q6 To what extent has your training prepared you for meeting the needs of the average child you work with?**



**Q7 To what extent has your training prepared you for working with children on the autism spectrum?**



**Q8 I would like the opportunity to develop my skills and knowledge for working with children on the autism spectrum.**



## **Appendix 14: Translation of flipcharts (The Study Day)**

### **Group 1**

#### **First question -**

- Early discovery
- Reliable diagnosis
- Early intervention / suitable plans (Ages 0-3)
  
- Provide a supporting and a convenient environment
- Develop potentials/therapists/ educators
- Enabling parents
- Provision for education (Ages 3-6)
  
- Provide a supporting environment
- Develop potentials (sensory therapy, clinical psychology)
- Individual assistance
- Inducing research/ statistics
- Providing therapy sessions for support throughout school years
- Special education for kids who are not able to be included (School years)

#### **Second question**

- Providing a clear data base for professionals
- Forming a national committee from different institutions and schools
- Setting clear rules and regulations by governmental institutions to control the work of the institutions working with autism
- Collaboration between autism professionals and the practitioners in the field

#### **Third question**

- Regarding the first step, application is hard in the mean time
- Implementing the steps in section one as initial interventions
- Directly supporting and assisting the existing institutions
- Networking between the different institutions and centers

## Group 2

### First question

- Issuing a written, clear and binding ministry policy
- Forming a national committee that includes all segments of society to follow up on policies and plans
- Building a database and doing statistics
- Building capacity for provision
- Providing a suitable and welcoming environment for inclusion (eg. Through community awareness campaigns)
- Adapting the syllabus to suit the students with special needs2

### Second question

- Forming a committee for cooperation and identifying responsibilities, goals, vision and message
- Using the available resources
- Developing a web forum for all the autism centers and institutions

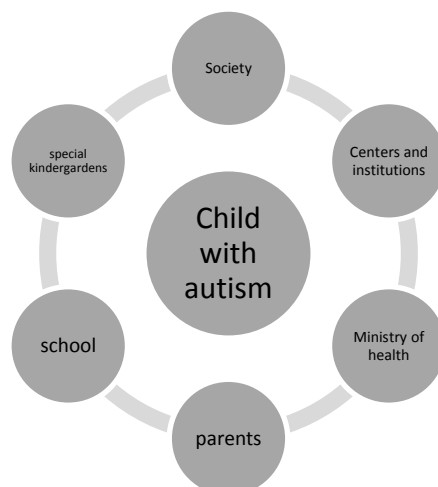
### Third question

- Assigning teacher assistants
- Providing a suitable environment
- Providing the suitable tools and materials for children with autism
- Creating an appropriate environment through forming a specialized team that follows up on the child's needs
- Forming a specialized committee

## Group 3

### First question

Priorities:



- Quality
- Diagnosis- There is no reliable diagnosis or a professional team for regular diagnosis
- Establishing organized centers and institutions
- Conducting research and an assessment of needs
- Including children with autism in the health insurance

### **Second question**

The need for networking between organizations

- Networking between parents
- Collaboration between doctors, institutions and professionals under ministerial supervision
- Creating electronic web pages

### **Third question**

- Enactment of laws
- Focusing on changing the environment around children with autism
- Teacher training
- Allocating budgets
- Setting firm and clear policies on how to help children with autism
- Providing competencies (music therapy, art therapy, water therapy, speech therapy)

## **Group 4**

### **First question**

- A national comprehensive plan (government, civil institutions)
- Setting goals and indicators to evaluate the plan and measure its success
- Building human capacities (through training teachers. Doctors, counselors)
- Raising awareness about autism in society
- Preparing a convenient physical environment for children with autism in the house, school or neighborhood.
- Agreeing on common strategies to educate and rehabilitate children with autism
- Creating a unified database that is easy to access and that includes all the available data about autism in Palestine

### **Second question**

- Periodical meetings between the different parties through workshops, conferences, seminars
- Exchange of expertise between different parties through media, press or social networks
- Forming pressure groups, local committees or coalitions that work and cooperate with the different parties and coordinate between them

### **Third question**

- Early and correct diagnosis
- Comprehensive and continuous follow up

## **Group 5**

### **First question**

- Training practitioners
- Rehabilitating buildings
- Increasing awareness about children's rights generally and children with autism specifically
- Working on changing the attitudes toward children's rights
- Founding complementary programs and information sources that are available for everyone
- opening a national diagnosis center and a training center

### **Second question**

- Starting a web forum for networking
- Founding a body that serves as an umbrella for the different institutions and parties working with autism
- Working on forming pressure groups to advocate the rights of people with autism

### **Third question**

- Linking the right of education for children with autism with the overall policy
- Urging educational bodies (eg. Ministry of education) to enhance the role of local community as a partner in the education process and inclusion

## Appendix 15

List of supplementary appendices on the CD (those included in the Thesis are shown in bold)

<b>Group A</b>	<b>Interview schedules</b>	
1	<b>Interview schedule –community providers</b>	<b>Appendix 2</b>
2	Interview schedule – key school staff	CD:A2
3	Interview schedule – the Ministry	CD:A3
4	Interview schedule – community providers	CD:A4
5	Interview schedule – parents	CD:A5
<b>Group B</b>	<b>Ethical review documents</b>	
1	Confidentiality agreement for the translator	CD:B1
2	Job description for research assistant / translator	CD:B2
<b>Group C</b>	<b>Case study – research instruments and forms</b>	
1	Participant information – Parents	CD:C1
2	<b>Participant information – school staff</b>	<b>Appendix 4</b>
3	Participant consent form – Parents	CD:C3
4	<b>Participant consent form – school staff</b>	<b>Appendix 3</b>
5	Child assent form	CD:C5
6	<b>Initial staff questionnaire</b>	<b>Appendix 1</b>
7	Initial focus group questionnaire	CD:C7
8	Evaluation (FGS)	CD:C8
9	Observation nudge sheet	CD:C9
10	Observing communication	CD:C10
11	<b>Observation and assessment profile</b>	<b>Appendix 6</b>
12	Focus group stories guidelines	CD:C12
<b>Group D</b>	<b>Transcribed interviews and analysis (Data set 1)</b>	
1.	Transcribed interviews – Parents	CD:D4
2.	Transcribed interviews – Teachers	CD:D1
3.	Transcribed interviews – Practitioners	CD:D2
4.	Transcribed interviews – Community providers	CD:D3
5.	Transcribed interviews – Ministry of Education	CD:D5
6.	Transcribed interviews – Universities	CD:D6
7.	Example of theme analysis –Parent	CD:D7
8.	Example of theme analysis – Teacher	CD:D8
9.	Example of theme analysis –Practitioner	CD:D9
10.	Example of theme analysis – Community provider	CD:D10
11.	Example of theme analysis – Ministry of Education	CD:D11
12.	<b>Example of thematic grouping</b>	<b>Appendix 9</b>
<b>Group E</b>	<b>MoE workshop – research instruments and forms</b>	
1	Participant information and consent form	CD:E1
2	Programme	CD:E2
3	An overview of the four data collection tasks	CD:E3
4	<b>Introductory questionnaire</b>	<b>Appendix 5</b>



<b>Group F</b>	<b>MoE workshop – questionnaire (Data Set 2a)</b>	
1	<b>Introductory Questionnaire - Collated responses</b>	<b>Appendix 10</b>
2	Data analysis Grid 1 (Question 1)	CD:F2
3	Data analysis Grid 2 (Question 2)	CD:F3
4	Data analysis Grid 3 (Question 3)	CD:F4
<b>Group G</b>	<b>MoE workshop – Focus Groups (Data Set 2b)</b>	
1.	<b>Focus group 1 and 2 - Transcriptions of group feedback</b>	<b>Appendix 11</b>
2.	Focus group 1 and 2 – summary of feedback	CD:G2
3.	Focus Group 2 – Theme Map	CD:G3
4.	Focus Group 3 - Translation of flipcharts	CD:G4
5.	Focus Group 3 – Flipcharts (photo)	CD:G5
6.	Focus Group 3 – Theme Map	CD:G6
<b>Group H</b>	<b>Case Study (Data Set 3)</b>	
1	Staff questionnaire data grid 1 (open questions) FGSCD:H1	
2	Staff questionnaire data grid 2 (closed questions) FGS	CD:H2
3	Staff questionnaire data grid 1 (open questions) ABC CD:H3	
4	Staff questionnaire data grid 2 (closed questions) ABC	CD:H4
5	Focus Group questionnaires – collated responses FGS	CD:H5
6	Example of completed questionnaire FGS	CD:H6
7	Focus Group questionnaires – collated responses ABC	CD:H7
8	Example of completed questionnaire ABC	CD:H8
9	Researcher's classroom observations	CD:H9
10	Example of a participant's completed Assessment Profile	CD:H10
11	Evaluation of the Assessment Profile – collated responses	CD:H11
12	Example of a completed evaluation of Assessment Profile	CD:H12
13	<b>FGS staff questionnaire – presentation of data</b>	<b>Appendix 12</b>
14	Sensory checklist	CD:H14
15	<b>ABC staff questionnaire – presentation of data</b>	<b>Appendix 13</b>
16	FGS evaluation – collated responses	CD:H16
<b>Group J</b>	<b>Study Day (Data Set 4)</b>	
1	Executive summary of research report for Qattan	CD:J1
2	Study Day Programme	CD:J2
3	Study Day participants	CD:J3
4	Study Day questions	CD:J4
5	<b>Translation of flipcharts</b>	<b>Appendix 14</b>
6	Thematic analysis of Q1	CD:J6
7	Group leaders briefing sheet	CD:J7