

Charles University in Prague  
Faculty of Education

# **The Influence of Parental Participation on Pupils with Autism Spectrum Disorder**

Yun-Ya, Huang

This dissertation is submitted in part fulfilment of the joint degree of  
MA/Mgr. Special and Inclusive Education . Erasmus Mundus  
University of Roehampton, University of Oslo and Charles University

Dissertation supervisor: PhDr. Mgr. Pavlína Žumníková Ph.D.

Autumn 2013

# Abstract

Parental participation takes an important part for the development of children with autism spectrum disorder. This qualitative research focuses on the influence of parental involvements on autistic children. The data was conducted by semi-structured interviews with open-ended questions which are the ways to understand parent respondent's perspectives particularly the things could not be observed directly such as opinion, belief, feelings, attitudes, knowledge questions and intentions. Three parent participants who have autistic children studying in mainstream primary schools in Prague, Czech Republic participant in this research.

This research is to probe the importance and the influence of parental participation on children with autism spectrum disorder. My research question stems from a wish to understand the influence of parental involvement on autistic children, and the barriers affecting the interaction and relationship between autistic children and typical developing pupils. Therefore, my research methodology is based on interpretivism research paradigm and qualitative research. Three main themes emerged from the findings discussing about the influence of meaningful parental involvement on children with autism spectrum disorder, the difficulties parents face, and the barriers of social interaction to children with autism spectrum disorder. Results indicate that the influence of meaningful parental involvement has a positive impact on children with autism spectrum disorder in relation to academic achievement, social skills, and daily living skills.

**KEY WORDS:** autism spectrum disorder, parental participation/involvement, social interaction, barrier, (inclusive)

# Acknowledgement

Firstly, I would like to thank European Commission offering me the scholarship to fulfil the study of Masters Programme in Special and Inclusive Education; thank Dr Jan Šiška, Dr Leda Kamenopoulou, Dr Jorun Buli-Holmberg for lectures and guiding my research. I would like to express my deep gratitude to my supervisor, Dr Pavlína Šumníková, for her guidance, feedback, caring, and patience. Special thanks go to the parent participants and Mrs E. Kocveldová, I would not conduct my data without their helps. Moreover, I would also like to thank EM SIE 2<sup>nd</sup> Cohort who I spent a great time with; and the support of Roehampton University, University of Oslo, and Charles University. My research would not have been possible without their helps.

Finally, I would also like to thank my parents and my sister who are always supporting me, encouraging me and standing by me through the good and bad times. I also want to give my thanks to M. Power, M. Lynch, M. Last, and Anne Welsh who inspired me to do further study regarding autism spectrum disorder.

# Table of Contents

	<b>Pages</b>
<b>Title Page</b>	
<b>Abstract</b>	I
<b>Acknowledgement</b>	II
<b>Table of Contents</b>	III
<b>Chapter 1- Introduction</b>	1
1.1 Introduction	1
1.2 Background and motivation of study	2
1.3 Purpose of study	3
<b>Chapter 2- Review of the literature</b>	5
2.1 Introduction	5
2.2 Definitions and features of autism spectrum disorder	5
2.3 Definitions of parental participation	9
2.4 The significance of parental participation	10
2.5 Barriers of social relationship for children with autism spectrum disorder	12
2.6 Peers' social interaction intervention for children with autism spectrum disorder	14
<b>Chapter 3 - Research Methodology</b>	17
3.1 Introduction	17
3.2 Research role and ethical concerns	17
3.3 Research paradigms and research design	18
3.4 Participants and Sampling	19
3.5 Data collection	20
3.6 Approach to data analysis	23
3.7 Methodological Strengths and limitations	27
<b>Chapter 4- Data Analysis &amp; Discussion</b>	28
4.1 Introduction to data analysis	28
4.2 The influence of parental involvement	28
4.3 The difficulties parents face	32

4.4 The barriers of social interaction of children with autism spectrum disorder	37
<b>Chapter 5-Evaluation and conclusion</b>	45
5.1 Introduction to the findings	45
5.2 Main research findings	45
5.3 Conclusion	49
<b>Bibliography</b>	V
<b>Appendix A</b>	IV
<b>Appendix B</b>	XV

# Chapter One

## Introduction

### 1.1 Introduction

This paper is related to the influence of parental participation on pupils with Autism Spectrum Disorder. This paper has five parts. The researcher's background, motivation and purpose of study will be firstly introduced in chapter one to have an overview of this study. The second chapter covers the literature reviews including the related empirical research with regard to parental participation as well as some theories such as Ecological Systems Theory, Social Learning Theory and Social Development Theory. I connect my study with empirical research and theories to probe the importance of parental involvement and the influence on children with autism spectrum disorder. Moreover, chapter three introduces the research methodology, sampling, and ethical discussion of this study to provide with a frame of conducting this research. Furthermore, chapter four discusses and analyses the collected data from the interviews. The findings are also included in this chapter. I hope to answer my sub-questions to research question to probe if parental involvement affects pupils with autism on their academic achievements, social skills, and daily living skills. Additionally, I hope to investigate whether parents-autistic children interactions affect the social interactions with other pupils in school; moreover, I hope to investigate the barriers of social interactions of autism spectrum disorder which affecting the relationship between autistic children and typical developing pupils. Lastly, the evaluation and conclusion are addressed in chapter five. The positive findings are to encourage parents to participate in autistic children's activities or events in schools or at home.

The aims of this study was threefold: (a) to probe social and affective factors that might affect the autistic children (b) to encourage parents who have children with autism spectrum disorder to involve in activities to increase children's social initiations, social interactions and social skills (c) to investigate the barriers of social interactions of children with autism spectrum disorder in schools and at home.

## **1.2 Background and motivation of study**

According to the estimation of the centres for Disease Control and Prevention (2012), one out of eighty-eight children are diagnosed as autism (cited in Sansosti, Lavik, & Sansosti, 2012). My voluntary experience in London with autism inspired me to do further study with respect to special education particularly autism spectrum disorder. During the year in the organisation, I discovered parents' expectation and experiences take important parts for pupils with autism spectrum disorder, which are the parts needed to be valued in Taiwan.

The concept of disability and special educational needs has gradually changed in Taiwan. Back in 1983, Feng-Qiao Incident aroused public awareness with regard to the discrimination and segregation towards people with disabilities. The first public petition as well as parental movement for their children with special educational needs was emerged and to endeavour to overcome the segregation of people with disabilities in Taiwan and to protect the rights for people with disabilities and special needs to live in local communities. In 1984 another petition was made by parents aiming to request the equal right to education for pupils with disabilities. The related-special educational policies were made after parental petition thus enabling the children with special needs to be educated equally. After the movements, in recent years in Taiwan, empowerment of parents and encouragement of parental involvement in decision-making in schools has been emphasised. Taiwanese Special Educational Needs (SEN) pupils benefit from legal requirements from The Special Education Act (Amended 1997, 2013) Article 5, 6, 28, 30-1, 46, and 49 which give parents more rights associated with parental involvement including special educational needs assessment, diagnosis, placement, Individual Education Plan (IEP) making, school policy-making; also provide the lectures, consultation, parenting education for the special needs family (Ministry of Justice, 2012). Hence, parents, defined as married parents, unmarried parents, local authority, foster parents, residential care workers or guardians (Special Educational Needs Code of Practice, 2001:16) nowadays are more active than before in several perspectives of schooling such as diagnosis, assessment, and intervention in Taiwan; the responsibilities are divided and shared with professionals and parents. Nevertheless, more well-structured and detailed regulations such as England's Special Educational Needs (SEN) Code of Practice are needed in order to clearly define the involvement obligation amongst parents, schools, and Local Education Authorities (LEAs).

Practically, according to two research conducted in the primary schools in one of the counties (Taoyuan County) in Taiwan in 2004 and 2006, about sixty per cent of parents with SEN children had participated in IEP meetings (Sun, 2009: 193). Sun's research also shows that parents who have SEN children are willing to spend more time participating in IEPs, conferences with teachers, and to obtain the support and services SEN children need and hoping to have more opportunities to communicate with teachers.

Furthermore, according to *Country Report: The Czech Republic* conducted by Hradec Králové University (2008), parents are obligated to participate decision-making such as placement (i.e. choosing schools) and Individual Educational Plan (IEP) in Czech Republic. Europe Agency for Development in Special Needs Education (2010) also explicates the importance of seeking parents' approval and perspectives if assessment of the placement and additional support (e.g. medical support) are needed; parents also have the right to reject the decision of placement. Nevertheless, parental participation (i.e. volunteering) in mainstream schools with autistic pupils are not yet paid much attention to neither in Taiwan nor in Czech Republic, where I conduct my research. Special education has changed from segregation, integration and gradually to inclusion. The initial notion of inclusive education in mainstream schools was first introduced in 1978 when the Warnock Report was published; however parental participation has not been recognised until recent years. Williams & Chavkin (1989) pinpoint the first essential element of a strong parent involvement is to have written policies that 'legitimized the importance of parent involvement and helped frame the context for program activities (p.18).' The policies should not set up for parents, but 'include' parents to cooperate as part of the partnership. Therefore, both school and parents can have a constructed standard or guideline to understand how to partake of the responsibilities. Parents could follow the guidelines which are provided by the government and professionals in order to support pupils with special needs appropriately in the first place particularly at the time when parents and school need to know what to do for the next step.

### **1.3 Purpose of study**

People with autism spectrum disorder have distinguished features including impaired social interactions and communication yet human beings connect with each other and build up relationships via social interactions. Other disabilities may be identifiable from the



appearance yet most of autistic children may not be distinguished easily by the appearance until you speak to them; therefore people with autism spectrum disorder may be easily ignored due to their lack of intuitive understanding causing difficulties to predict and participate in the social interactions with others. Two participants from a study describe they find it difficult to build up social relationships with others due to a 'wall', a metaphor used by participants, as self-defence to protect themselves from the hurt of others (Lin, Knox, Barr, Chiu, & Chung, 2006). Therefore, both participants prefer to be alone and keep a distance from people since they would not be disappointed and hurt if there is no expectation. For the people with disability and special needs, it is more difficult to be included in society in consequence of their 'differences'. People would have fewer chances to build up a connection, attachment and understanding with people with disability and special needs by reason of the lack of reciprocal social interactions, which is a main part of the connection with people and this is a precisely difficulty for people with autism spectrum disorder.

The primary purpose of this research is to probe social and affective factors that might affect the autistic children. The secondary aim of this study is to encourage meaningful parental participation. The third aim of this study is to investigate the difficulties autistic children might have in school and at home. In addition, this study also investigates both advantages and barriers of inclusive educational setting. I hope this study could also provide an overview of children with autism spectrum disorder studying in mainstream school (inclusive setting). I am interested in parents-autistic children interactions and I hope to see if it influences autistic children on their social interactions with other pupils. I hope this study benefits for not only autistic children but also non-special need children to gain an understanding of autism spectrum disorder particularly bring up public awareness and concern of social difficulties and barriers for pupils with autism spectrum disorder nowadays.

# Chapter Two

## Review of the Literature

### 2.1 Introduction

This chapter is firstly related to psycho-social conditions of autism spectrum disorder. The definition and features of autism of both clinical aspect and social dimension will be introduced in the first place to have an overview of both models, and then I will introduce some related neurobiology theories including neuro-cognitive: theory of mind deficit, weak central coherence, and executive function to provide with a clearer understanding of medical model and social model of autism. Moreover, some empirical research in relation to parental participation, social interactions of autism and peers mediated intervention for children with autism will be addressed to support the theories stated above. Finally, there are also some sociology theories with regard to social learning. I hope to link these theories with autism spectrum disorder to investigate the social initiations, social interactions, and social responses between autistic children and others.

### 2.2 Definitions and features of autism spectrum disorder

The concept of autism has changed since Leo Kanner first identified autism in 1943, when autism had misconceptions such as the emotional disorder of autism causing by insufficient parenting; most autism were firstborn or the only child (Mesibov, Adams, & Schopler, 2000). Later definition of autism by The *Diagnostic and Statistical Manual of Mental Disorder Fourth Edition Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000:51-52) concerns social difficulties, communication impairment and restricted behaviours. Trembath, Germano, Johanson, & Dissanayake (2012:213) describe ‘ASD is an umbrella term used to describe a group of lifelong pervasive developmental disorders, which include autistic disorder, Asperger’s disorder, and pervasive developmental disorder–not otherwise specified (PDD-NOS).’ Frith & Hill (2003) sum up autism as a ‘developmental disorder characterised by impaired social interactions and communication as well as repetitive behaviours and restricted interests. (p. 1)’

There are several possible causes of autism yet the actual ones remain unknown. Some believe that environmental factors have an impact on autism; some believe it could be vaccine that causes autism. Even though the exact causes of autism are uncertain, medical model gives the perspectives of genetic factors and neurobiology to explain and to understand autism.

#### Genetic factor: inherit and fragile X syndrome

Research show that autism runs in families with respect to genetic components. Marshall (2004) indicates there is a possibility that the families who have autistic children could also have a pattern of autistic disorder or related disabilities. According to a research of Johns Hopkins School of Medicine, ‘approximately half of all close relatives of autistic children have milder symptoms of autism (cited in Marshall, 2004:21).’ To be more specific, the study shows chromosomal abnormality ‘fragile X syndrome’ is identified amongst autism. Bauman & Kemper *et al.* (1994, 2005:251) explicates ‘approximately 2-6 percent of males with autism have fragile X syndrome, and 15-33 percent of children with fragile X syndrome have autism.’ In addition, Marshall (2004) indicates males are affected four times more often than females, which is related with the fact that males have only one X chromosome. Other chromosome abnormality such as chromosome 7, chromosome 15 could also be the reasons causing autism.

#### Neurobiology: brains and nervous system

Ritvo (2006) describes autism as developmental syndromes, which are influencing a person’s development ‘due to abnormal development of certain parts of the brain (p. 25).’ Frith & Hill (2003) indicate autistic brains on average are bigger and heavier than normal brains; and the size of brain increase around at the age of two to four. In addition, there is less connection between occipital and superior temporal sulcus, a function for social and speech perception, in the autistic brains than in the normal brains. Frith & Hill (2003) point out research have provided the evidence that there are structural abnormalities in autistic brains.

Of particular interest are the findings of reduced neuronal cell size and increased cell packing density in regions of the limbic system known to be critical to emotional and social behaviour. Outside the limbic system, abnormalities have also been found in the cerebellum and in various cortical regions.

Frith & Hill, 2003: 4

Human brains are solely a part of the nervous system. Additionally, Frith & Hill (2003) address autism spectrum disorder from the perspectives of three main neuro-cognitive

theories: *theory of mind deficit*, *weak central coherence*, and *executive function*. First, theory of mind deficit hypothesis proposes that there would be a difficulty to understand certain basic communication if there is a fault in the components of social brain. Moreover, autistic children would be impaired in their intuitive understanding of mental states such as beliefs to themselves and others, which is ‘mind-blindness.’ Baron-Cohen, Leslie & Frith (1985) demonstrate in an experiment that autistic children have different reaction from normal developing children. Moreover, ‘children and adults with autism have also shown to have deficits in their understanding of pretence, irony, non-literal language (e.g. double bluff) and deception (e.g. white lies) (Frith & Hill 2003:6).’ Furthermore, Frith & Hill (2003) also show a dysfunction in a network of brain processes and mentalises the tasks demands in the brains of people with autism spectrum disorder. This network involves the *medial prefrontal cortex* (especially anterior paracingulate cortex), *the temporal-parietal junction* and *the temporal poles* (p.7).

Secondly, Sperber, & Wilson (1995) indicate people with autism spectrum disorder could not transfer the environmental stimulus and process existing information to meaningful coherent messages. For instance, Frith & Hill (2003) find autism could not understand a homographs test such as ‘tear in the eye or in a piece of fabric (p.9).’ Thirdly, Ozonoff, & Jensen (1999) propose that the damage of frontal lobe could be the cause of autism thus resulting withdrawal and aloneness, concrete thinking, self-centred interactions, and limited interests.

From the perspective of medical aspect, autistic brains have abnormalities in the area of processing social and speech perception. As a result, the children and adults with autism find it difficult to interact with others due to the lack of intuitive understanding, which is the essential part of social interactions, to observe and to analyse the context of social activities. Traditionally, medical model, dominated many fields including Special Education, tends to define disability and impairment with the lack of capacity or malfunction of individuals from the perspectives of brain, genetic factors, neurobiology or pathology. Bury (2000) defines ‘disability as a restriction or lack of ability to perform an activity in a normal manner. And the main cause of restriction of activity is illness or impairment (p. 179).’ Medical model focuses on pathology with neurobiology in order to find out the causes as well as solutions or treatments. Nevertheless, physical condition should not be the barrier. On the other hand, social model looks on a different dimension from the attitude of society instead of individual

limitations or disadvantages. Social model emphasises on the problem originates from the social oppression. In other words, disability is not the individual problem but society's problem (Barnes & Mercer, 1996). Finkelstein (2001a) considers the people with disability encounter a problem: 'You see disability fundamentally as a personal tragedy or you see it as a form of social oppression (p. 5).' Social model explicates disability is a social problem thus the method to eliminate it is to adjust the social environment such as protest, establish the disability association in order to protect the rights of the disability instead of asking them to be accustomed to the society (French, 1993). People with disability should not be treated as things that can be 'fixed'. Admittedly, it would not be merely personal problem or only the restrictions of the society. Apparently, it is essential to be able to accept and change with a different concept and attitude toward the perspective of individual as well as social nowadays. Social model emphasises the society should accommodate all instead of changing individuals with disabilities. People with disabilities should be included equally in society. To wholehearted 'accept' the people with disability is difficult, however, it should be considered as a social process to make it a better inclusive society. As Rovinelli & Gitterman (2011) suggest both medical model and social model should be further developed and promoted therefore parents of autistic children could seek for the interventions they need and combine public and private sources. Also, 'at the same time, society would begin to understand the need to embrace all individuals, including those with autism (p. 267).' To achieve the vision of inclusion, the accessibility and the support for autism spectrum disorder should be considered and done first in order to accommodate all.

### Medical treatments

Under medical model, medical treatments such as Fenfluramine, megavitamins, major tranquillisers, and Naltrexone are used to lighten the symptoms of autism. Fenfluramine, for instance, is a medicine to reduce the blood level of serotonin, which is a natural chemical founded highly in approximately a third of autism. Yet, the evidence has shown the possibility of using Fenfluramine could result in damaging the nervous system in animals (Baron-Cohen & Bolton, 1993). In addition, megavitamins (e.g. high doses of vitamin B<sub>6</sub>) seems harmless to health however studies show if the vitamin B<sub>6</sub> treatment stops, sometimes the disturbance increases (Baron-Cohen & Bolton, 1993). Medical treatments could temporarily ease the symptoms of autism however the side effects and health concerns of autism should be firstly considered. As Blatt *et al.* (2010) point out the pharmacotherapy for autism spectrum disorder

is overall disappointing. Baltt mentions the treatments of hyperactivity and irritability are successful; however ‘evidence of efficacy with respect to core symptoms of impaired social interactions and communication is weak (p. 261).’

### **2.3 Definitions of parental participation**

Parental participation or involvement literally describes as to participate in the activities and learning at school or at home, including school's decision-making, volunteering as helpers at school, and the effective communication with professionals (Epstein & Dauber, 1991; Hornby, 2000). To be more specific, Epstein explicates six types of involvements that parents are supposed to basically provide children with a ‘positive home conditions’ and regularly communicate with school in terms of child’s progresses in school meanwhile parents should assist their children at home on learning activities coordinated with the school assignments with the guidance provided from teachers. Furthermore, participate in decision making of schooling and connect with agencies and other groups are recommended in order to meet the *Basic obligations of families, Basic obligations of schools, Involvement at school, Involvement in learning activities at home, Involvement in decision making, and the Collaboration and exchanges with community organisations* (Epstein & Dauber, 1991: 290-291). More recently, Jacob (2010:12) states ‘Parental involvement can be reflected through both behaviour (e.g. communication with the child about school, help with homework, etc.) and beliefs (e.g., expectations and aspirations for the child’s academic achievement or educational attainment).’ Therefore, parental involvement indicates that parents participate in all kinds of learning activities at home and at school individually or with the support from local communities and experts. Parental participation shares the cooperated partnerships amongst school, homes and communities. Comer & Haynes (1991:273) further develop the levels of parent participation in school: general participation as level 3; helping in classrooms or sponsoring and supporting school programmes as level 2; and parent participation on the level of school planning and management as level 1.

According to the Special Educational Needs (SEN) Code of Practice, parental involvement includes the initial stage of identifying the support that SEN children might need, choosing mainstream or special schools, making IEPs as well as reviewing IEPs termly, the resources or the support that SEN children and parents need from LEAs, voluntary

organisations and schools, and the Statutory Assessment Tests SEN children will take such as General Certificate of Secondary Education (GCSE). The Curriculum Guidance, which is an important guidance for early childhood education in England, describes that ‘parents are central partners in their child’s education and practitioners need to work effectively with them (QCA/DEFF, 2000; cited in Fitzgerald 2004:1).’

## **2.4 The significance of parental participation**

Bennett (2012) pinpoints the best treatment for autistic children is the need for parental participation. The importance of parental participation is shown in both policies and research. Traditionally, schools are considered as authorities in education. Nevertheless, *The Salamanca Statement* (UNESCO, 1994) states ‘the education of children with special educational needs is a shared task of parents and professionals (p.37).’ Hence, it is not solely schools’ but also parents’ responsibilities to shared task with respect to support pupils with special needs. Bennett (2012) also indicates lack of parental participation could be harmful to autistic children’s development due to incapability to support or meet the needs of children with autism.

Allred & Edwards (2000:437) mention ‘over the years, numerous studies have shown that parental attitudes towards and involvement in their children’s learning activities in the home and at school have an influence on children’s level and quality of learning, development and attainment at all ages.’ Parental involvement undoubtedly has the significant impact in early years to shape a child’s character and development; and the influence may continue to adult years. As Bennett (2012) points out parental participation has a positive effect on increasing developmental skills and progress in an early intervention programme. A study by Baker (1997) illustrates the importance of parental involvement, highlight as many different opinions and perspectives as possible, and builds on the theory and practice regarding strengthening school-home partnerships.

Research has shown the benefit and influence of parental participation on both children with SEN and children without SEN. Research have shown that the earlier and more parents are involved, the better and longer effects on children’s development last. The advantages of parental participation are numerous. Firstly, from the perspective of development, it is beneficial and significant toward children’s development. ‘The involvement of parents in their

children's education is now widely accepted as desirable and even essential to effective schooling (Comer & Haynes, 1991:271).' Academically, the influence of parental involvement in children's development has been demonstrated by research showing that parental participation 'influence children's acquisition of reading is of potentially great importance' (Sénéchal & LeFevre, 2002:445). Another study by the National Literacy Trust (McCoy & Cole, 2011:4) supports the viewpoint that 'Parental aspirations and expectations on their children's achievements have a strong impact on children's school results.' Secondly, parents generally have a better understanding than anyone else of issues affecting their children. Thus, parental involvement is beneficial for the pupils with special needs to clarify their learning as well as future paths. Keyser (2001) pinpoints that families know about family issues including family history, culture, or health whereas school has the knowledge of the school setting, development, and curriculum. England's SEN Code of Practice (2001) states parents have the key information and play a significant role in children's education. Parents have the knowledge and experience to support their children; therefore, it would be more effective for both professionals and parents to include parental perspectives of their children's developments especially to children who have special educational needs. Furthermore, schools are not the only educator. There is no doubt that schools are the places provided with well-equipped facilities and trained teachers to educate pupils yet school education takes solely a certain period of time whereas family's influence is lifelong particularly the period of the early childhood development. A study by Kellaghan, Alvarez & Bloom shows that before pupils reach eighteen years old, they spend thirteen per cent of time learning in school and the rest of the time about eighty seven per cent is influenced by family (Cited in Hou, 2007:15). These figures suggest that only a small percentage of children's learning takes place in school and mostly the learning takes places in non-school settings.

Admittedly, several research have shown the importance of parental participation in schools. Fan & Chen (2001), for instance, explain their finding supporting the importance of parental involvement in relation to pupils' academic achievements such as GPA. Fan and Chen logically show the importance of parental involvement using meta-analysis to analyse and synthesise the relation between parental participation and pupils' educational achievement. They collected ninety-two correlation coefficients between parental involvement and pupils' academic achievement from the twenty-five studies. The data revealed that parental supervision at home such as homework supervision has the weakest influence however parental expectation for pupils' academic achievement has the strongest



one particularly whilst the educational achievement is shown by a global indicator such as GPA than a subject-specific indicator such as maths score. Importantly, ‘this finding confirms the intuition harboured by many educators and researchers, that parental involvement and students’ academic achievement are positively related (Fan & Chen, 2001:12).’ Another finding of Fan & Chen represents the weak relationship between parental supervision and students’ academic achievement, yet parental expectation has a significant influence on pupils’ academic achievement. Baker’s (1997) study illustrates the importance of parental involvement; highlight as many different opinions and perspectives as possible; and builds on the theory and practice regarding strengthening school-home partnerships. Baker indicates parents who volunteered in the school believe it is beneficial for the children by helping teachers do their jobs better which eventually benefited their children because parents generally ‘believe the importance and value of being involved at the school and in their child’s education’ (Baker, 1997:134) and parents feel like experts on their children. Moreover, from the perspective of development, it is beneficial and significant toward children's development. ‘The involvement of parents in their children’s education is now widely accepted as desirable and even essential to effective schooling (Comer & Haynes, 1991:271).’

## **2.5 Barriers of social relationship for children with autism spectrum disorder**

Baron-Cohen & Bolton (1993) suggest some therapies such as behaviour therapy, social skill training, psychotherapy, music therapy, speech & language therapy, holding therapy and daily life therapy could help autism to accommodate in society. Take social skill training for instance, Baron-Cohen & Bolton (1993) explain there are certain kinds of social skills training would be taught such as making phone calls, going shopping, or behaving on the bus according to social conventions. Generally, social skills can be taught even though autistic children or adult may forget something or look unnaturally since they learnt it systematically rather than acquire social behaviours subconsciously. Nevertheless, ‘empathy’ or ‘sensitivity’ to others’ feelings and intentions are the parts therapists find it most difficult for this social skill training.

Bushwick (2001) indicates for children with severe autism, people are ignored as objects so basically there are no social interactions between severe autism and others. Milder children

with autism lack of participation of social initiations and social behaviours such as greeting others. Research show autistic children participate in some degree of activity and social interactions; nevertheless, autistic children, compared to normal developing children, spend time mostly in non-social activities or play at a distance from others. Admittedly, children with autism also directly participate in a social play with others however only with a small proportion of time and rarely use eye contact. A research by Kennedy & Shukla's (1995), as cited by McConnell (2002), indicates that autistic children are not isolated at all times, they participate in social conditions with pupils and families however they are able to receive and respond fewer social initiations, and tend to 'engage a shorter bursts of interactions. (p.354)' Social initiations, defined as 'approaching a person and giving or showing him or her an object, prompting someone to engage in an activity, pointing to or reaching toward an object, or verbalising one or more understandable words (Krantz, MacDuff, & McClannahan, 1993:137).' McConnell (2002:354) mentions an observation conducted by Lord and Magill-Evans explicating children with autism spectrum disorder 'had lower-quality interactions when they did play with peers, and spent more time engaged in purposeless or no activity and/or at greater physical distances peers' thus receiving less social initiations and verbalisations from people surrounding them such as peers and adults.

Research indicates that people with autism spectrum disorder could be supported by computers to develop some social skills. Also it is important for people with autism to be in a comfortable, safe, predictable, low environmental stimulation place (e.g. the seating arrangement in the classroom), meanwhile coordinated with teaching techniques such as attitudes and gestures thus enabling to engage autistic children in social interactions (Robins, Dautenhahn, Boekhorst, & Billard, 2005; Su & Zhou, 1994). Also there are some more recent studies supporting this. A research with regard to robotic assistant in therapy and education for autistic children shows people with autism would be more comfortable and have more social interactions or responses whilst they are playing the games or activities in predictable settings; particularly enjoying interacting with computers which is the isolated objects autism would pay attention to (Robins *et al.*, 2005). Moreover, it could be the reason that 'computers can break into this world by focusing the individual's attention tunnel on the screen, so that external events can be ignored more easily (p. 106).' Robins *et al* (2005) point out human-human interactions is difficult to predict and interpret due to the differences of social and cultural norms, the understanding of people's motivations and emotions, and the differences of body gestures. Therefore to interact with robots could provide with a controllable and

predictable environment for people with autism to gradually acquire social skills. Based on the finding of the observations, autistic children pay more attention and have more eyes gaze to the robot, supporting the notion that robots are appropriate and possible for engaging children with autism in social interactions.

A study by Krantz *et al.*, (1993) demonstrates a positive influence by using a picture activity at home which not only decreases some disruptive behaviour (e.g. aggression or self-injurious behaviour) but also increases social initiations and interactions between family and autistic children. It indicates parents could increase the social initiations to engage autistic children with structured activities in a safe and predictable environment. These activities including photograph activities at home supporting by parents; robotic social therapy; and using modern technology such as iPod Touch, video, computers to engage children with autism in daily living skills and social skills learning (Krantz *et al.*, 1993; Buggey, Hoopes, Sherberger, & Williams, 2011; Cihak, Smith, Cornett, & Coleman, 2012; & Johnson, Blood, Freeman, & Simmons, 2013). The results are mostly positive. Research suggest teaching children with autism from age of 5 to 9 structured social-dramatic plays (i.e. specific social skills) to increase some degree of social interactions.

## **2.6 Peersøsocial interactions intervention for children with autism spectrum disorder**

The influence of peer-mediated has also addressed in some research. McConnell (2002) points out the importance of peer-mediated intervention which increases the interactions and social behaviours between non-SEN children (i.e. classmates or siblings) and children with autism in inclusive and natural settings such as schools or homes. McConnell also addresses the importance of the age of children in inclusive setting because autistic children would have more social interactions and long-lasting social initiations with older peers who could initiate autistic children five times more than younger pupils. Moreover, both academic and social responses increase whilst arranging academic tutors with both non-SEN children and children with autism (Kamps, Barbetta, Leonard, and Delaquadri, 1994). This study by Kamps *et al.*, (1994) shows the effective peer-mediated strategy, Classwide peer tutoring (CWPT), could benefit for non-SEN pupils and SEN pupils (i.e. autism) on academic subjects (e.g. reading, spelling, mathematics) in regular educational setting. Additionally, CWPT requires high-level

of social interactions thus meanwhile enabling students to perform appropriate social interactions and skills.

McConnell (2002) describes the social skill training, such as free play activities, may vary however modelling is significant for autistic children could acquire social skills by observing models (e.g. elder peers, teachers and parents) who could demonstrate a structured, predictable and appropriate social interaction for children with autism. As Bandura's Social Learning Theory (1977) states children learn by observing others around them such as teachers, characters on television, friends and parents, who researches have shown the importance of parental involvement; later on children might copy behaviours they have observed. 'Social learning theory approaches the explanation of human behaviour in terms of a continuous reciprocal interaction between cognitive, behavioural, and environmental determinants (Bandura, 1977: vii).' Moreover, children may consider what happen to other people then choose not to copy certain behaviours they have observed due to different circumstances. Unfortunately, people with autism have difficulties to transfer the environmental stimulus and process existing information to meaningful coherent messages since the ability to choose what to copy is a complicated cognitive information process. Bandura emphasises the motivation and self-regulation would influence a person's behaviour. The four strategies 'attention, retention, reproduction and motivation' seem applicable social skills for autism. Some empirical researches also show there is a possibility for people with autism spectrum disorder to observe and copy the behaviours from the people such as parents around them. Additionally, McLeod (2007) mentions Vygotsky's theory states that social learning tends to precede development, and individual development learn through the social and cultural context. He also stresses on the Zone of Proximal Development, which children accomplish independently with a skilled tutor through social interactions.

Under Bandura and Vygotsky's theories, there should be a possibility for autistic children learn or have social imitations and interactions from observing their classmates, and surrounding adults who would be the skilled tutors to support autistic children to achieve certain socialised behaviours through the framework of scaffolding. McConnell (2002) points out relative structure of activities for autistic children could influence their social interactions; and more structured activities would bring higher rates of social participation. Bennett (2012) also reviews some research indicating that children response better and more organised to structured activities (National Institute of Mental Health, 2004; Ozonoff & Cathcart, 1998,

cited in Bennett, 2012). Moreover, children with autism spectrum disorder have more social initiations and response; and engage more in social interactions with elder companies. A case study conducted by Wu & Yang (2002) shows the autistic child (high-function autism) changes her functional play (e.g. repetitive patterns of behaviours) into symbolic play (e.g. the demonstration of creativity) through scaffolding; and later on, it is likely to increase the varieties and complicities in her plays. Thus, it is possible for children with autism to have reciprocal social interactions with others through social stimuli (i.e. the peers play group) as well as scaffolding with skilled adults (i.e. the teacher). One of Wu & Yang's findings shows the importance of skilled adults. Wu & Yang point out the skilled tutor has to have a guideline first in order to assist and observe the interactions between the autistic child and other pupils in the first place. In addition, the teacher needs to select the appropriate toys, which are directly connected with the themes of the plays. Thirdly, the teacher also needs to arrange the environment including space or decoration of classroom to avoid the distraction or influence on the autistic child. Another research by Mundschenk and Sasso (1995) demonstrate that 'social interaction increases as a function of the number or proportion of typically developing children in a play group who have received explicit training in social interactions skills (cited in McConnell, 2002: 359).' It is not easy to support a child with autism spectrum disorder, however, this is the spirit of social model, which suggests using resources and support to accommodate and facilitate autistic children in this society.

# Chapter Three

## Research Methodology

### 3.1 Introduction

This chapter introduces my research methodology and how I conduct my research. In the first parts of this chapter I will bring up my research role and the main ethical concern. In addition, I will address my methodological approach and explain how I choose my research paradigms, research design, sampling process and participants for this study. Moreover, I will explicate the method of conducting this research, progresses of data collection including interview preparation, interview process; and elaborate more detailed ethical issues which may arise in different stages of conducting this study such as ethical considerations in data collection, in data analysis, interpretation, and writing up. Furthermore, the approach to data analysis will be introduced to have a clearer overview of how to categorise, analyse and interpret collected raw data. Lastly, methodological strengths and limitation of this research will be discussed.

### 3.2 Research role and ethical concerns

In a research, the influence of researcher's role on the study should be firstly taken into consideration. Robson (1993) brings up a question concerning whether 'the study help to solve the problem or throw light on the issue presented (p.450)'; Robson suggests doing research should make it practical and provide applicable solutions, resolutions or answers to the context of the research. The researcher should also estimate the costs and benefits of the research, protect the dependence of the research as well as ensure the quality of the research. Moreover, ethical issue is also an important part of research.

Ethical considerations pervade the whole process of research; these will be no more so than at the stage of access and acceptance, where appropriateness of topic, design, methods, guarantees of confidentiality, analysis and dissemination of findings must be negotiated with relative openness, sensitivity, honesty, accuracy and scientific impartiality. Cohen, Manion & Morrison, 2007:57

Creswell (2009:88) also suggests that ‘ethical practices involve much more than merely following a set of static guidelines, such as those provided by professional associations.’ Creswell points out researchers should consider the protection of participants during recording and coding; moreover, it is proposed discarding the data after analysing it in order not to fall it into others who may misuse it. Admittedly, the ethical issues do not solely arise in the process of collecting and analysing data but relate to all processes of conducting research, so the researcher should also address considerations such as proper language or words that may contain biases. Furthermore, ethical issue should not be solely focused on moral dimension so I will also link it together with the research methods which researchers use for the processes of collecting information, analysing data and writing up the research, as elaborated below in different sections.

### **3.3 Research paradigms and research design**

My research question stems from a wish to understand the influence of parental participation on autistic children, and in what way it also influences the interactions between autistic children and their typical developing peers. As a result, my research methodology is based on interpretivism research paradigm and qualitative research. Thomas (2009) explains in the social sciences paradigms refer to two approaches, positivism and interpretivism, depending on how we search for knowledge and use it. Thomas indicates the key of interpretivism is *understanding*, which describes as to be interested in and understand people’s views and perceptions of the world; also, use this understanding to interpret and explain perspectives and behaviours of people. As Professor Kent (2012) presents, Interpretivism research paradigm is ‘an attempt to describe and understand a dynamic social world of which the researcher is a part. Focus on deep description of meanings, interpretations, perceptions and actions—the constructions of participants in interactions/the cultural rules of situations.’

Additionally, research frame provides a scaffold to construct my research. Maykut & Morehouse (1994) describe qualitative studies as a designed method to discover some social phenomena in which people are the subjects. The original qualitative data I obtain would be broad, rich and in-depth, allowing for different things to be discussed and discovered. Besides, the outcomes of qualitative data such as motivation or the intension behind the

factual figures have profound understanding of experience which is statistics data and figures could not explain. Robson & Foster (1989:91) indicate that ‘one of the major strengths of qualitative research is that the data have life and emotion’. However, ‘qualitative research has been criticised for its lack of certainty (Robson & Foster, 1989:86).’ As a researcher, I would carefully analyse and interpret the qualitative data in order to reduce uncertainty and subjectively interpretation that might exist.

### **3.4 Participants and Sampling**

The criteria for research samples should be considered and planned carefully once research question is formed. Sampling is an important procedure to conduct information in a research. Selecting the population (the target group) and good data (the actual group in which the data are collected) are important otherwise the results could be misleading since the data represent the population value (Punch, 2009). Nevertheless it seems to be unlikely for researchers to observe or talk to every individual in the population directly. Therefore, I gather information from selected individuals who match the criteria for my study. Maykut & Morehouse (1994) suggest in the qualitative research, participants should be carefully selected for inclusion so variability in different social phenomena is included in the data. As a result, nonprobabilistic sampling, more specific, a generic purposive sampling approach is selected purposively in terms of certain participants based on several criteria to answer the research question. Furthermore, Weiss (1994) suggests to choose samples purposively if samples are smaller than 60 to provide with examples of meaningful developments which occur infrequently instead of choosing random sampling. Based on this sampling method, a total of three parent respondents participate in this study.

#### Process of sampling

Initially, due to the language barriers and samples’ availability, I hoped to collect convenience samples which researchers use based on samples’ availability rather than selecting samples based on research criteria. However, fortunately, from my supervisor’s lead, a source is provided to connect with a mainstream primary school where some autistic children attend. This mainstream primary school follows the national curriculum with students from Year 1 to Year 9, providing various activities and secondary school preparation as well as assistants, psychologists and a special educator.



After contacting with the special educator and presenting my sample criteria, four parents who match the criteria are selected and invited to participate in the interviews. Later on, four parents are consulted their willingness and consent to participate in this study. However, only three parent participants who have autistic children agree to participate in the interviews at last. Two of their autistic children are at the age of primary school, ranging from approximately nine to eleven years old and another autistic child is in his teens. Parent participants and their children are given aliases to prevent from being recognised. Tomas, Parent 1's (Natalie) son, was two years older than his peers when he studied in this inclusive primary school; now he is studying in a special school after he finished his primary education. Lukas, parent 2's (Anna) son, is now a Year 5 student who was integrated in his class since Year 1. He was diagnosed as middle-function autism at the age of 3, since then his parents and family have been supported and trained him. A year after he was then diagnosed as high-function autism. Jakub, parent 3's (Eliska) son is a Year 3 student who was diagnosed as Asperger syndrome at the age of five.

Three parent participants have already been through the periods of being aware of children's developmental delays, diagnoses, assessments and the treatments of early intervention. Moreover, the participants have at least one or two other children who are non-special educational need, therefore the parents would have noticed the difference between autistic child and their siblings during developmental processes; the social interactions in between would have been also observed and compared by parent participants beforehand. Furthermore, two parent participants are professionals who have the experience working in mainstream schools to closely observe the social interactions between their autistic children and other students. Lastly, their autistic children are attending mainstream primary schools; one of the autistic children is now attending special school after graduated from mainstream primary school. Thus, my study is based on an inclusive setting in a local area in Prague, Czech Republic.

### **3.5 Data collection**

#### Method for data collection

My data-gathering tool is interview because 'depth interviewing probes beneath the surface, soliciting detail and providing a holistic understanding of the interviewee's point of

view' (Patton, 1987:108). I am interested in finding out contemporary parents' expectations and individuals' experiences; one of the strength of interview is interview questions vary such as opinion, belief, feelings, attitudes or knowledge questions so evaluators could collect broader and deeper data. In addition, interview, a purposive conversation, seems to be a direct method and shortcut to get the information straightforwardly from respondents, to interact with respondents, and do follow-up questions during the interview, which are what questionnaires method could not offer. Therefore, interview seems to be a more suitable tool for collecting information for my research. More specifically, semi-structured interviews are conducted. The data are collected as primary source of data by using in-depth interviews and open-ended questions which are the ways to understand people's perspectives particularly the things we cannot observe directly such as feelings and intentions. Robson (1993) indicates once choosing semi-structured interviews, researchers should have a specific topic but may be guided by participants' responses, and researchers would seek to cover the topic through flexibility in wording, sequences of questions, and the related themes that covered in the topic.

Additionally, open-ended questions allow participants to express more freely and openly as they wish thus enabling gathering broad and deep data as well as any additional information. Cohen and Manion (1989), as cited in Robson (1993: 233), describe open-ended questions:

They are flexible; they allow the interviewer to probe so that he may go into more depth if he chooses, or clear up any misunderstandings; they enable the interviewer to test the limits of a respondent's knowledge; they encourage cooperation and rapport; and they allow the interview to make a truer assessment of what the respondent really believes. Open-ended situations can also result in unexpected or unanticipated answers which may suggest hitherto unthought-of relationships or hypotheses.

An interview guide, which guides my interview questions as a reminder, is prepared for me to follow it carefully and closely during the interviews. This interview guide contains interview schedule and questions with specific scopes of themes, possible questions, possible follow-up questions, and probes is used as an interview guide; however, I have the flexibility to enquire, to modify, to explain or do follow-up interview questions during the process of interview. Jacob & Furgerson (2012) suggest some tips for interviews as firstly to arrange to interview in a quiet, semi-private place; and consent form should be collected before

interview starts. Jacob & Furgerson then recommend starting with the script researcher prepared; using recording devices which allow researcher only take short and quick notes in the process of interview and still be able to remain eye contact with respondents; using basic counselling skills to help respondents feel heard such as showing interest for the their talks, listening more than speaking and keeping focused during interview; finally, ending with the script. Robson (1993:234) introduces five sequences of questions as *introduction*, *warm-up*, *main body of interview*, *cool-off*, and *closure*.

Additionally, some skills of communication matter. It is important to ask clear and specific questions as Patton (1987) suggests that evaluators should know how to ask clear questions during interviews, because unclear questions could make interviewees feel confused or uncomfortable.

‘Being clear about what you are asking contributes to the process of establishing and maintaining rapport during an interview. Using words that make sense to the interviewee, words that are sensitive to the respondent’s context and world view, will improve the quality of data obtained during the interview’ (Patton, 1987:123)

Moreover, interviewers should avoid proposing questions such as biased questions which may lead participants to researcher’s predetermined responses. Furthermore, as Robson (1993) addresses that interview could be time-consuming (i.e. arrangement, practice and preparation before interviews, transcription) and could be difficult to rule out biases thus raising concerns with regard to reliability. Robson also implies the length of an interview appears to be invaluable if it is under half an hour; and longer length interview may influence sample sizes and may end up causing sampling bias. Interview techniques of control and closure are also important as to control the flow at the appropriated time.

Furthermore, researchers could initially carry out analysis during data collection instead of classify and analyse a big amount of data at the same time. Robson (1993) suggests reading through the notes taken during interview because it generally includes some ideas, thoughts, suggestions, and perhaps gestures which audio-recording could not show. Later put these notes as an addition into interview scripts to reflect on the interview condition so it helps as a reminder. I also prepared a session summary sheet after each interview that summarises background information of participants, issues that were raised or covered, some more suggestions, what I have found out so far, and highlight what needs to answer. Meanwhile, I

start to develop further my original coding categories to make it clearer when it comes to analysis.

### Ethical issues in data collection

Creswell (2009) pinpoints many ethical issues arise during the stage of data collection. Therefore, several ethical procedures and considerations during data collection should be anticipated such as gaining the permission of gatekeepers to request the access to study participants in the first place, thus seeking for the approval would be my first consideration. In addition, I explain my purpose of study, confidentiality issues and provide a written consent form for my parent participants before interviews start. Therefore, participants have clearly understanding that I will record during interview in case of respondents' comments missing; keep their confidentiality; and also they may withdraw from the interview anytime if they are not willing to or have their own concerns. Moreover, both the researcher and participants should benefit from the research; therefore, there should be reciprocity between the researcher and participants. The possible harmfulness to participants during the data collection should be also anticipated (ie. anonymity of participants).

During the process of interview, Interview questions could be sensitive to the interviewees, so I also take ethical issues into consideration. For instance, parent participants could bring out a controversial issue regarding special educational needs or autistic policy during interview and I will consider how to present the information in my writing. As Cohen, Manion & Morrison (2007) suggest that sensitive issue concerning participants themselves, their family, and their teachers may reveal in interviews, and researchers also should decide how to deal with the information especially negative findings.

### **3.6 Approach to data analysis**

The original qualitative data are broad, rich and in-depth, allowing for different things to be discussed and discovered. The outcomes of data have a profound understanding of experience. Robson & Foster (1989) define analysis as 'a meticulous sorting of information whereas interpretation is a *Eureka* moment when suddenly the researcher gains insight into the meaning implicit within the data gained (p.85).' Belenky (1992) mentions a term *interpretive-descriptive research* to explore studies which depend on participants' words and

meanings for data to analyse (cited in Maykut & Morehouse, 1994). The researcher should not only collect rich and in-depth data of parental participation but also read beneath the surface on a deeper level to understand the background of the study as well as participants' thoughts, intentions, motivations, concepts of value and feelings. After collecting data, it is necessary to analyse data because raw data do not simply show the messages that hidden in the recording or script. Research could also have a glimpse of the basic of the interpretation while analysing data.

### Procedure of data analysis

Data are mainly words or numbers so I am also prepared for dealing with qualitative and quantitative data that may exist. Analysis is likely to be the most difficult part of conducting a research. Main task of analysis is to find the answers to research question. Therefore, the analysis should be fairly treated without biases. As Fetterman (1989), as cited in Robson (1993:374), indicates that 'analysis is a test of the ability to think-to process information in a meaningful and useful manner.'

After collecting the raw data such as field notes, audio-tapes, and documents, Maykut & Morehouse (1994) suggest the raw data should be transferred and typed quickly into clearly readable form for analysis, and the data should be identified and studied as chunks or units of meaning for what is significant to the participants instead of researchers' predetermination. In addition, the data should be analysed and read objectively to demonstrate the perspectives of the participants. Therefore, my collected data are transcribed from the recordings of interviews as soon as possible after conducting the interviews, and the raw data will be read through again in order to gain the overall information and to reflect on its meaning.

Robson (1993) sees 'codes' as symbols to identify specific responses and to simplify these responses by categorising them into smaller and similar groups. Nevertheless, Robson (1993) indicates the coding process is likely to lose some information. I firstly, as Robson suggest the procedure of coding, put all responses into a piece of paper with the question on the top, and label the case number for each response; afterwards, I try to classify the responses into eight to ten similar and small groups. Also every code has its own label (i.e. name) in order to relate to other categories easier and to avoid confusion. Hence, the raw data is organised and sorted with similar groups such as similar ideas, sentences or paragraphs; and shortly classified them into core categories, and the sub-categories which relating to the core

categories. By following this process, I try not to lose the information which may seem to be irrelevant yet it may have its meaning. In addition, I read through each line for several times whilst classifying all responses into smaller groups, it makes the later process of interpretation easier than analysing as a main theme. Each similar group is categorising regarding to research topic as Bogdan and Biklen (1992:166-172) suggest:

- Setting and context codes
- Perspectives held by subjects
- Subjects' ways of thinking about people and objects
- Process codes
- Activity codes
- Strategy codes
- Relationship and social structure codes
- Reassigned coding schemes

Furthermore, the data is then subcategorised according to research questions:

- Of what general category is this item of data an instance?
- What does this item of data represent?
- What is this item of data about?
- Of what topic is this item of data an instance?
- What question about a topic does this item of data suggest?
- What sort of answer to a question about a topic does this item of data imply?
- What is happening here?
- What are people doing?
- What do people say they are doing?
- What kind of event is going on?

(Bryman, 2012: 575)

The codes are reviewed regularly and carefully in relation to my transcript of interviews in order to evaluate the connections between the codes, and to reflect on my findings for the research questions. After categorising those data with terms, I re-examine the interrelating themes, description, literature and theories to interpret the underlying meaning of data, which

is the final step of data analysis. Robson (1993) pinpoints researchers should interpret the context and the data instead of stating sufficient information.

### Ethical issues in data analysis and interpretation

Ethical issues may also arise whilst the researcher analyses and interpret data. Creswell (2009) suggests that first consideration in the research is to protect the anonymity of individual, and then the analysed data should be kept for a period of time (i.e. five to ten years) to prevent from misusing by others. Generally speaking, personal information such as the identity of the participants could be highly distinctive and identifiable in some cases in research. The private data which may identify participants should not be reported. Hence, I will protect the anonymity of my parent participants, as Kvale (1996) suggests changing participants' names and some identifying features. The quotes from the interviews could be presented however any information that is identifying the anonymity of the participants would be removed. In addition, I would inform my parent participants in advance with regard to the treatment of collected information as well as my findings.

### Ethical issue in Writing up

Furthermore, I would be careful with the word-choices to avoid using the language, words, or terms which contain negative or biased meanings against people because of 'gender, sexual orientation, racial or ethnic group, disability, or age' (Creswell, 2009:92). As a researcher, Eisner & Peshin (1990, cited in Kvale, 1996: 117) point out the research should have 'the sensitivity to identify an ethical issue and the responsibility to feel committed to acting appropriately in regard to such issues.' Particularly in qualitative research, which takes in-depth perspective of parental participation, I avoid adding labels, bias and researcher's concept of value into the research. Additionally, researchers should not invent the findings to meet researchers' needs so the findings would be according to the collected data directly from participants. Lastly, Creswell draws on the importance of releasing the details of the research such as study design so readers could evaluate the study. As Cohen, Manion & Morrison (2007) describe, 'whatever the specific nature of their work, social researchers must take into account the effects of the research on participants, and act in such a way as to preserve their dignity as human beings: responsibility to participants' (p. 58).

### **3.7 Methodological Strengths and limitations**

Admittedly, language barrier is the main limitation for conducting my research during the process of literature review in the beginning such as reading specific policy documents without English version or with English description of the related laws yet a few documents or websites, which caused the lack of knowledge of Czech Republic. The parent respondents who participant this research have passion for their children's wellbeing. The collected data is richer and broader than I had expected. Parents are willing to show me some more additional information about their autistic children yet there is also a difficulty to interview participants because they find it difficult to speak in English thus accompanying by an interpreter to translate during the process of interview is a must. Due to language barriers, I missed out some information such as some jokes, facial expression and timings to do follow-up questions during the process of interviews at that moment.

From methodological aspect, my collected data from qualitative research is rich, enormous and broad for researchers to seek for the meaning within, however qualitative research is also judged as the lack of certainty. Therefore, as a researcher, I am careful in every processes of conducting this research in order to avoid subjectively and biases particularly whilst doing sampling, analysing and interpreting data. Additionally, some information may be seemed as irrelevant data and it could be ignored whilst coding data into smaller groups. Hence, I read through the interview script regularly to review and reflect on the interpretation.





# Chapter Four

## Data Analysis and Discussion

### 4.1 Introduction to data analysis

There are three themes with regard to parental participation emerged from the data I collected. I transferred and classified the data into three main themes and six subthemes discussing about how parents are involved, the influence of parental involvement, the difficulties parents face, what are the barriers to parent involvement, parents' experiences, expectations and concerns, and the barriers of social interactions of children with autism spectrum disorder.

In the beginning of this chapter I will address the influence of parental involvement, including the support parents give their autistic children, the support parents seek for when their children were diagnosed as autism, and the activities parents involved in school and at home. Moreover, the difficulties parents face including parents' experiences, expectation and concerns will be elaborated as theme two. Lastly, I will further develop the issues of schooling, including inclusive setting, peers acceptance, the social relationship between autistic children and other typical pupils, and the barriers of social interactions of children with autism.

### 4.2 The influence of parental involvement

First of all, from the perspectives of policy and school, parents should be fully involved in the school-based response for their children to understand the purpose of any intervention or programme of action and be told about the parent partnership service when SEN is identified. Moreover, parents are also expected to regularly communicate with professionals to support the children as well as to fulfil the obligations under home-school agreements (SEN Code of Practice, 2001:17&18) since parents could provide with their experiences and an understanding of their children which could assist professionals to arrange the appropriate

academic and social activities. Reynolds (1992) indicates that a better parents-schools relationship with regard to parental involvement could develop children's positive attitude towards schools thus resulting in educational achievement instead of linking merely problem behaviours with home-schools connection. Additionally, LEAs and the voluntary sector should work to ensure that parents receive comprehensive, neutral and appropriate advice and have information on the full range of support services (SEN Code of Practice, 2001: 18). Parents should also have the right to determine decisions in relation to children as well as to cooperate with professionals if needed, and every step that a school makes is on behalf of the child therefore parents' permission should be first consulted and keep them informed at all times.

#### Activities parents involve at home and in school

The first category shows the ways and levels parent participants are involved, both at home and in school. It illustrates that parents are not just fully involved in one event but also they are involved in different events such as going field trips, assisting in other areas of the school, summer camps, going for some programmes (e.g. counselling, early intervention programmes) and assist children's homework. Barnard (2004) indicates parent participation is conceptualised a frame with traditional measure and other elements of parental participation. Parent 1 has the experience going to school trips with her autistic son. The trip lasts for one week and all students in the class attend. Parent 2's child does not wish to go to school trip alone so Parent 2 trained her son since Year 1 to go to summer camp and try to learn to be on his own. Hence, Lukas (Parent 2's son) could just go to summer camp or field trips with his assistant now. Parental involvement is not solely physically involved in activities but also participate in children's lives. Both Parent 1 and Parent 2 attend some courses every year in an organisation provides educational and related family support programmes for special needs family (i.e. autism) or educators in the local areas. Parent 1 attends some courses such as how to work with autistic children in the organisation. Parent 1's participation was more intense in the beginning when her son was younger. She not only supports the educational activities in school but also participates actively in daily routines at home. For instance, she was involved at all levels of life in the activities every day after school including helping with timetables management, and assisting her son for art session at home. Later, gradually she decreases some amount of time of involvement for her son while

he is more capable of handling things on his own. Gradually, Parent 2 also hopes to decrease the assistance from his assistant in the future thus enabling her son to be independent such as learn how to cope and deal with different things might happen by himself.

Moreover, Lukas finds it difficult to read books due to dyslexia, so he prefers to search for information such as space and nature on computers. As previous literature reviews illustrate that computer is an effective tool for people with autism spectrum disorder to develop some social skills and academic achievement due to the reason that computer could intensively attract people's attention on the screen. In addition, if he is interested in some books, Parent 2 would spend time reading with him. Parent 2 mentions they firstly read one of the best-selling novels together, and then they spent time watching the film adapted by this novel afterwards.

#### Positive influence of meaningful parental involvement on daily living skills, academic achievement and social skills

Barnard (2004:41) states 'there is evidence to suggest that parent involvement at home (i.e. monitoring of school activities and encouraging learning activities) is associated with child's achievement.' By involving in various activities with their autistic children, parents establish a firm relationship with their children. Parent 2 states her child *now it can be a quite progress about the summer camp. He doesn't like to be away from his family but from this year he starts to write letters in the summer camp which makes them sad because he writes that he's not with them with his family and family should be together.*

Chamberlain, Kasari, & Rotheram-Fuller (2006) also single out the importance of parental involvement which could make great improvement of social interactions for high functioning autism. Temple Grandin, a famous autism author who was listed in Time magazine of the 100 influential people in the world in 2010, also mentions the importance of her parents who supported her for a one-to-one early intervention programme since she was diagnosed as autism at the age of two. Furthermore, Baker (1997) discusses the main barriers to parental involvement are mostly the constraints of time, money, scheduling, transportation, and child care. Sun's research (2009) also points out the main reasons why parents could not participate in IEP meetings in schools are mainly because parents do not have time to be involved in IEP meetings, or parents have no opinion on teachers' decisions.

Parent 1 mentions her son could not speak until the age of four and he could not understand words because he has problem with perceptions. However, *Now he's much better.[....] now he's able to travel to school on his own and back on his own.* Ecologically, children with special educational needs will socially establish the relationships starting with family and gradually other people. As Bronfenbrenner (1979) describes, children benefit from building a firm linkage in mesosystem, the communication between two different microsystems, such as community-home relation, home-school relation, school-community relation, and the relation between SEN children and family-of-origin. Bronfenbrenner implicates children and adolescents' developments are profoundly influenced by the environment factors (i.e. microsystem, mesosystem, exosystem and macrosystem). Admittedly, autistic children could firstly build up a firm connection with families, teachers, and peers and gradually expand the connection and interactions to community and society. Comer & Haynes (1991) pinpoint that meaningful parental participation is beneficial and essential for children's development particularly connected with ecological approach.

A literature review organised by Chiang (2008) states there are almost eighty per cent of autistic children in Taiwan do not have daily living skills to live independently. Generally speaking, taking care of persons with special needs seems to be family's responsibility. Families are considered as the main caretakers who would support and seek for solutions for their special need family. Parents mainly concern about the well-being of their children, more specifically, parents worry about 'who else' could be the main caretaker to look after autistic children when parents are incapable of taking care of them. Parent 2 then describes the methods they train him for daily living. For example, families of parent 2 trained Lukas to accept the variety of foods so he would also have to eat the food even he does not fancy. Additionally, they would go to a restaurant to select and order meals; however, now they have a challenge which Lukas could not join a table with strangers, so they attempt to make a small progress each time to see if he would be able to. Moreover, families of Parent 2 would take children for shopping and gradually Lukas is able to do basic shopping such as buying some beverages or pizzas in the corner shop near their house on his own. Furthermore, he also learnt how to share things with his younger brother, which was difficult in the beginning; therefore, parent 2 set the rules and time for them to obey such as to create some activities or games together during play time. Parent 2 also directed them to play together for five minutes in the beginning and then gradually increased the time spending on games together. Parent 2 mentions the great progress Lukas achieved, he now learnt how to play with his younger

brother and they could play together for a longer time spontaneously, counting as hours instead of minutes.

From academic perspective, the reviews of literature mostly have the positive findings showing the significant impact of parental involvement on children's school achievements. Reynolds (1992) surveys 481 children for investigating parental participation in school and at home regarding academic achievement (i.e. mathematics and reading), and Reynolds finds teacher rating of parental participation in school shows positive influence on academic achievement; parent rating and children rating of involvement in school and at home also illustrate its importance yet relatively small. Reynolds (1992:457) points out 'children may, as a result of their parents' activity in school, develop more confidence in their ability, show greater motivation, and experience a greater sense of cohesiveness with their school that enables them to perform better.' Children in the survey also indicate the influence of parental involvement is related to educational achievement. Socially, Rogers & Pennington (1991), as cited in Bushwick (2001), indicate if autistic children failed to develop imitation in early childhood, it may result the defectiveness of social behaviours and it would be more complex and affected following development. Parents have significant influence on autistic children's social interactions, and they would assist their children to judge if the social behaviours are appropriated. Parent 3 mentions there is a communication book for parents to know about her son's assignments and performance at school. *'If there were any behavioural problems etc., at home I try to speak with him about the school situations, try to explain him reasons of behaviour of his classmates and also I accompany the class when needed for example trips to the zoo, school trip, and some sport events (Parent 3).'*

### **4.3 The difficulties parents face**

#### Parents' experiences

Parents however face problems in dealing with emotional and practical difficulties (Rogers, 2007:98). Every parent naturally expects to give birth to 'perfect and normal' children. Emotionally, parents go through feelings of shock, denial, disappointment, and acceptance after the child is diagnosed with special educational needs. It is reasonable that some parents are upset and not ready to be involved in children's school life for a period of time, or specifically, do not know the most suitable approach for SEN children and how to

deal with the feelings at first. Parent 2 was shocked, stressed and uncertain whether they could manage this in the beginning, yet afterwards Parent 2 and her husband determined to support their son as much as they could. Parent 2 also brings up an issue concerning the shortage of social workers and special educators who work in special educational centre and visit schools to make individual programmes for each student with special needs. Parent 2 describes the special educators do not have enough time to come for the meetings due to the increasing number of children with autism spectrum disorder nowadays. Parent 2 then emphasises on the importance of social workers and special educators from special educational centre, who could assist and educate parents in the initiate stage when parents are confused what to do next.

Parent 1 is a knowledgeable professional who writes some articles in relation to autism. She describes she suspected that her son is an autism due to some familiar signs and syndromes she has read therefore it was not too surprising that her son is diagnosed as autism spectrum disorder. However, Parent 1 indicates there are still obstacles for autism to get the support because the recognitions and diagnosis are not easy. Parent 1 mentions it is easier for children with Down syndrome or children with physical disabilities to receive official diagnosis and support however *for autism it depends on the doctor, if he helps or not. Sometimes children with autism don't have support like that.* Here Parent 1 refers to the support such as manual of disability or free public transportation (i.e. trams). Parent 1 pinpoints other special need children may be much easier to be diagnosed due to the appearance however there is a difficulty to recognise autism. She describes:

*'If sometimes it is recognised, they don't think it's necessary to have such support. Some doctors still think autism as a modernised disease which was created by parents or some people who are unable to take good care of their children because of their behaviours. I have to say there are lots of people in our society still think this. It's especially children with some syndrome they just think they are just naughty.'*

Parent 3 starts from autism related books, and joins some courses in an organisation. Parent 3 also mentions she gets assistance from the autistic organisation which offers *'special programmes for parents with children, it's a kind training of behaviour in different social situations. And [the programmes] also help a lot to have a good cooperation between us, the class teacher, and the teacher assistant.'*

Three parents particularly Parent 1 had a difficult time during diagnostic process going from doctor to doctor to do diagnosis and assessments due to a lack of understanding or misconception of autism in society at that time thus resulting receiving official diagnosis at the age of six, which should be at the age of three according to American Academy of Pediatrics (Sansosti, Lavik & Sansosti, 2012). At last, parent respondents were relieved and glad to know and confirm what actually happened so they could make effort and search for support for their sons. As Sansosti, Lavik & Sansosti (2012) explain the reason parents seeks for professional opinions and the diagnosis is to seek for the answer and recommendation to their child's difficulties with regard to social interactions, behavioural, and communicative problems. Sansosti, Lavik & Sansosti also pinpoint the delay of giving diagnosis are the factors such as 'inadequate screening practices, poor early screening instrumentation, similarity of symptomatology with other disorders, and practitioners' slow responses to parent concerns. (p.82)' Therefore the longer diagnostic process takes, the longer frustration parents receive. Additionally, parents need a label for their children in order to understand the condition and to get support from the experts; Rogers' (2007: 96) research shows 'There are not always straightforward answers with regard to many of the children's impairments....yet it seems important for parents to know what is going on and how to deal with it.' Parent 3 also experienced this, she mentions '*on one hand we were shocked, but on the other, we were glad, that we got to know what the problem is and we are able to help him in some way of special treatment. I started to read books about this problematic and attended a couple of courses for parents of autistic children.*' Although it could be difficult for parents to live with the fact that the child is labelled with special educational needs especially facing the situation in the school meeting to discuss how their special needs child should be treated with groups of experts using special educational terminology. Based on an interview with a teacher, Clough & Nutbrown (2004) raised the concern that parents often find it painful and humiliating to hear of and accept their child's deficiency. Practically, parents look for support from the legislation and professionals' consultation to meet the needs of children with special educational needs. Nevertheless, parents could also find it difficult to determine the best way for the child with SEN.

As a single mother I began the *fight*: the fight for mainstream school, home schooling, no school and special school! I really did not know what I wanted, or indeed what was the most appropriate way forward for my daughter. What I did know was that however consuming 'the work' became (visiting professionals, reading books, paying for private consultations, carrying out extra homework and, of



course, mothering), I continued; what else I was supposed to do?  
(Rogers, 2007:18)

Additionally, not all parents participate in children's school life as actively and knowledgeably as the policies seem to expect. Parents may not participate in activities due to the lack of time and desire. Additionally, there may be some difficulties for school to facilitate and coordinate parents in school activities. The 'recurring theme in many studies and commentaries is that less educated parents cannot or do not want to become involved in their children's education (Baker & Stevenson, 1986; Lareau, 1987; cited in Epstein & Dauber 1991:290).' Besides, 'the role that was often attributed to parents over the next decades: good parents helped children by supporting what happened in nursery or school; bad parents held children back leading to supposed deficits' (Cited in Fitzgerald 2004: 3-4). Certainly, every individual has a different definition of 'good parent'. Vincent (1996) interviewed a teacher who describes the ideal parents as 'sensible and can see how to do things' (p. 93). Yet the teacher Vincent interviewed also raised the concern that if the parents do not have the qualities stated above, it will lead to a 'chaotic result' once the parents are left in the situation they do not know how to deal with. (p.93) Thus, the partnership and relationship between schools and homes should not be ignored. Parent 3 also emphasises on the partnership between home and school.

*'We are in the close contact with the class teacher and assistant of our son ó every day. We had a ðcommunicatorø special notebook in which the assistants write to us information about what happened at school, not only homework and things to do, but also how did he get during the day.'*  
(Eliska, Parent 3)

Nevertheless, it then brings out another issue which is the 'power' between the school and the parents. Munn (1993) explains the partnership 'denotes not only formal powers and obligations, but also interactions' (p. 149). Yet, school is generally presumed to be the professional educational authority, and the judgments a school makes are considered professional, too. Anyhow, the relationship between parents and schools should be based on a collaborative status. As Sharrock suggests, there are four areas for changing the relationship between home and school: 'changes in teachers' attitudes; increasing individualisation of contacts; the provision of information about modern educational trends; the greater involvement of parents in the life of the school (Cited in Wolfendale, 1983:46).' Reynolds (1992:459) also suggests 'parental involvement, to be maintained and enriching, must be reinforced by school practices as well as children's own experiences.' Furthermore, most

importantly, 'Kean (1991) points out that it was not only the specific education legislation that impacted on the education service, but also the overall constraints that were imposed on local authorities' capital expenditure and other financial arrangement' (Cited in Munn, 1993:152). Professionals and parents establish a process and policy to support and to meet the needs of SEN children. However, 'bureaucratic measures, finances and levels of need (low to high) dictate how the process, and then provision is delivered' (Rogers, 2007:99). Generally parents would already have the ideas such as early intervention activities for the children with special needs but it takes time to go through the administration process such as diagnosis and placement to get the resources or support, so the SEN children may miss the benefits and the best timing to receive early intervention in the initiate stage. Furthermore, the support parents seek mostly end up as merely 'official documents' (i.e. official diagnosis or manual of disability) and it may lead to a difficulty to integrate the support and recourses special need family could receive.

#### Parents' expectation and concerns

Every parent generally has expectation and concerns to their children. Parent 1 indicates now she has no big expectation because she has been experienced disappointment for many times thus trying to establish specific goals such as academic or social skills goals for her son would be more practical; and in a good way he could surprise her when he achieves the goals. The main concerns of parent 2 at first are about if her son could manage his life, for instance, if he could study or could take care of himself. A qualitative study by Chen (2006) illustrates the perceptions of seven mothers who have autistic children; seven parents all consider parents' role as caretakers, advocates, and educators for their children; and parents' role is connected effectively with their children's developmental goals. Parent 1 then express the strong family connection and affection.

*Heø get a younger brother, 14, and I think they really really have great relationship. The young one is prepared to take care of him when heø older. [í .] Itø not nice to say normal relationship but they really have it like that. They attended special programmes for brother and sisters of autistic children to physiologists and they learnt some technique to solve problems and conflicts and something like that.ø*  
(Natalie, Parent 1)

Academically, parent 2 hopes her son would attend a grammar school and take graduation examination in the future, she then describes the academic problem her son faces, which is the motivation of studying. Her son is very capable of learning but he does not fully understand the reasons why learning these. Parent 2 also pinpoints for her son everything seems to be either black or white (e.g. either perfection or total failure). It could be positive in a way that autistic children have higher standard yet they could be stressed and frustrated easily if they could not reach the high standard they have in mind. Everything could not be perfect after all and there is something in between- this is what parent 2 attempts to explain and show Lukas to see and experience from different perspectives in order to increase the motivation for future education including academic progress and daily living skills.

#### **4.4 The barriers of social interactions of children with autism spectrum disorder**

Schooling is also important for autistic children, Baron-Cohen & Bolton (1993) explicates children with autism truly improve in their educational development even solely with a few years of schooling. Hence, it would be very important to have an appropriate school well facilitating for children with autism spectrum disorder such as equipment and more importantly, teachers with skills and strategies to assist autistic children.

#### Positive outcome in inclusive setting

Parent 1 describes the most important and successful thing for her son to be in an inclusive educational setting is *not everything is adapted for him but he has to adapt to something. It's a big knowledge he appreciated.* Kamps et al., (1994) suggest a meaningful and successful inclusion context requires well-developing and planning to meet the social and academic needs for pupils with disabilities. Alderson & Goodey (1999) brings about the issue that which kind of schools is most suitable for children with autism spectrum disorders. The researcher uses observations and interviews in school to conduct a qualitative study of children with autism spectrum disorder in special schools and inclusive schools. Alderson & Goodey interviews 45 pupils, their parents, teachers, school governors, and local education authority staff during 1994-1996. The authors observed 22 schools in two very different local education authorities; East City which has an inclusive policy and West County which has

special schools and units. The main finding is about urgent questions concerning current educational theories, policies and practices of the pupils with autism. The author observes in the classrooms from several dimensions such as teaching techniques, disciplines, and the support offered to autistic children (e.g. therapy in an Autism unit in West County), and the author finds the problem is the staff ‘in some other schools were more kind and gentle, but we saw similarly low teaching standards and expectations, and no informed, consistent ways of responding to behavioural difficulties (p.257).’ Whereas the inclusive primary schools in East City seem to be more beneficial. One of the interviews shows a former special school teacher finds out severely affected autistic pupils noticeably improve when they are in the inclusive classes. Alderson & Goodey (1999) concede the inclusion is working on gradually in the schools however the education policies for pupils with autism should be reconsidered by all local education authorities.

It has been discussed for a long time regarding a better and suitable placement for children with special educational needs. The challenges of inclusive education nowadays are not only policy-making but also the placement, teacher’s competence concerning special education, curriculum, parent and pupil’s acceptance, and the integration of resources. Inclusive setting could bring more chances for autistic pupils and non-SEN pupils to interact. However, teacher training regarding special education and school facilities have also been important issues. Wu (2007) finds teachers who have pupils with disability in the class express their frustration such as sense of incompetence and helplessness. Moreover, teachers are considered as important roles for inclusive education; however the competences including knowledge regarding special education and the readiness for inclusive education are not emphasised and well-provided. Teacher-pupil ratios should be also taken into consideration to benefit both pupils with SEN and pupils without SEN. Furthermore, inclusive schools should provide with the exact facilities for the pupils with disabilities to increase more choices and options for pupils with autism to participate inclusive schools. Briefly, Baron-Cohen & Bolton (1993) suggest to place autistic children with other typical developing pupils altogether at school may increase more chances for SEN pupils to interact with other non-SEN pupils with respect to develop the public awareness and understanding of the special needs for others; however school facilities and resources including teacher-pupil ratios should be taken into account to benefit children with autism and to facilitate at all possible opportunities. As McConnell (2002) indicates that inclusive environment may not be sufficient yet is essential for providing with more social activities for both non-SEN children

and SEN children thus enabling to create and increase social interactions and responses for autistic children and typical developing peers. Three parent participants support the inclusive setting in schools and all have positive outcomes on their sons from inclusive setting.

Parent 1's son attends to special school after graduated from inclusive primary school. She mentions they consulted and discussed with psychologists regarding the transition from primary to secondary education. Roberts (2010) illustrates several considerations when planning transition for pupils with autism such as future career options, time-managing skills, academic support, and secondary study preparation are in the scope for consideration. For instance, it is important to consider the possible future careers to plan in advance to select the related subjects in school. Moreover, pupils with special educational needs should know the support that provided in school such as school facilities (e.g. accessibility, braille), and academic support including tutoring and advising. Roberts also suggests having a functional plan in order to guide and assist pupils with autism and parents during transition period. The transition plan or guide should contain an up-to-date individual information, instead of solely clinical diagnosis; individual educational plan; related services to be provided in the school; and the evaluations and goals in relation to academic or daily living skills. For parent 1's consideration, it seems to be more practical and useful to study in a special school since the mainstream secondary schools focus on academic aspect of knowledge which requires high amount of information process, and it may be difficult for her son to intensively sort the high amount of information. In contrast, special school offers the appropriate curriculum and individual educational plan which are both established well from both academic and practical perspectives for children with disabilities therefore it seems to be a better option for her son to attend special school in secondary level. She mentions in special school students are trained to work and volunteer once a week in some places such as university offices to do some photocopy and file documents. It is practical for their future life to learn daily living skills, to learn how to buy things in shops or to do simple mathematics such as counting money. However, parent 1 strongly supports the notion of inclusive education which enhances the educational environment for increasing social interactions between SEN children and non-SEN children.

*Maybe the most important thing he learnt to be a collective child to ask them if he needs something because it's a problem for him to ask. He sorted some rules are normal, [such as] to go to school every day, sit on the desk, do something is great and to be collective. And the main things is when he is in a normal environment, normal school, it helps him to be much better if he was in some*

*special school when everyone does everything for him. It was much challenging for him.* (Natalie, Parent 1)

*'Our son hasn't any mental problems so it's great he can be in mainstream school, every day he sees the normal behaviour. His problems are explained and shown how to solve them, and how to act in normal life.'* (Eliska, Parent 3)

### Peers acceptance

Chiang (2003:27) interviewed a mother when he conducted his research, and the respondent points out a notion concerning peers acceptance 'Everybody learns to take good care of him. Be nice to him, hold gently and all that kind of things, but would never include Eric any of their games spontaneously, get invited to a birthday party, get invited to play day, he is never invited anywhere....' According to a research by Alderfer *et al.* (2001), as cited in Campbell, Ferguson, Herzinger, Jackson, & Marino, 2005:295), it illustrates that 'prosocial behaviour enhances peers' acceptance of a child with chronic illness, more so than a child without a chronic illness.' By providing appropriate models, inclusive educational setting has its own significance for children with autism spectrum disorder to gain friendship and to increase social initiations, acquire social skills and academic knowledge. However, some studies reviewed and organised by Chamberlain *et al.*, (2006) show that children with disabilities in certain situation in inclusive setting could be rejected or compared to other peers thus causing the great loneliness. Bauminger & Kasari (2000), as cited in Chamberlain, Kasari & Rotheram-Fuller (2006), report the great loneliness children with high functioning autism feel than their pupils due to 'a confusing social world, in which conventional social signals may be misunderstood, resulting in increased risk of peer rejection and loneliness. (p.231)' Inclusion is not a total perfection, children with autism spectrum disorder may learn social skills or social interactions with typically developing peers, and however, they might be isolated or ignored due to their social inflexibility thus causing low confidence and low self-esteem. Temple Grandin (1995) states 'some people believe that people with autism do not have emotions. I definitely do have them..., such as fear, anger, happiness, and sadness (as cited in Chiang, 2011: 93).' Certainly, children with autism would be frustrated and confused about the situation. Therefore, the peers in an inclusive setting should firstly prepare to provide with some social skills for autistic children by skilled professionals thus enabling the positive and continuous effect of inclusion. Children should be provided with information well-explained concerning autism including the features and conditions. A study by Hsu and

Hsia (2000) shows autistic children's significant improvement with regard to social interactions and academic achievement in inclusive classroom, however, the peers mention they would not like to include autistic pupils in their classes if they were offered a chance to decide their pupils in their classes. Parent 3 describes the barrier of social interactions for her son, Jakub, '*Some are in his inability to understand the social context sometimes, especially humour or irony, also sometimes the problem is his stereotypical hobby, which may seem to the other children sometimes irritating.*' Therefore Parent 3 tries to explain to Jakub why his behaviour is inappropriate by providing some examples.

Parent 2's son experiences the difficulties discussing classroom works and establish a partnership with other classmates due to his 'either black and white aspect' which leaves no room for discussion so sometimes his peers would not wish to continue with it. During break time he does not engage too much playing with other children but prefer to play on his own or to eat something on his own. In general, younger pupils (i.e. Year 1 to Year 5) show more affections and willingness to help each other thus it seems unlikely a main problem for autistic children when they are in Year 1 to Year 5. A study investigates the effectiveness of social skill groups in general Year 1 classroom setting for peers with autism and their non-SEN peers (Kamps, Leonard, Vernon, Dugan, Delquadri, Gershon, Wade, & Folk, 1992). Kamps *et al.*, (1992) consider social skills groups as a group offers pupils to perform social behaviours such as social initiations, greeting, compliments, sharing in turns, and asking /providing assistance; they gained positive findings with regard to the social interactions amongst pupils with autism and non-SEN pupils in the social group. Parent 1 experiences this when her son was in Year 1 to Year 5. For parent 1's son, there was no problem for peers' interactions, children were willing to provide with support if needed; and there was also an assistant to support him in class. However, as Tomas and his peers got older, many of his classmates were changed to another class due to the studies for secondary school preparation; and meanwhile it is also the transition that children turn to adolescence, which is the period adolescent start to be aware of the differences (i.e. maturity, appearance) in between and choose the friends they prefer to engage with. Allan & Gilbert (1995), as cited in Chiang (2011), pinpoint in most of cultures, people with better physical competence represent better social attractiveness. However, pupils with autism generally perform lower physical competence due to motor impairments or sensory sensitivity; it may also be one of the obstacles to establish friendship for children with autism. As a result, Parent 2 describes her son is considered as childish due to the differences between Lukas and his classmates were

larger and noticeable as they are more mature, compared to Lukas. Chiang (2011) indicates high-function autism find it most difficult to process the complexity of information regarding social interactions. Peers may misjudge them or consider them as geeks or weirdoes particularly some autistic children who are with average or of above average intelligence. Furthermore, Yuan (2002) observes that female peers in lower Year tends to assist, protect, and have some physical contact (e.g. hugs) with autistic children however it seems to be inappropriate to have physical contact with autistic boys because of the developing of secondary sexual characteristics. It could possibly cause some confusion for autistic boys due to the sudden changes. Male peers would mostly tease autistic children or even worst, bullying. Dubin (2007) pinpoints the chance of being bullied for autistic children is four times higher than typical developing children. Therefore, parent 2 is concerned this as a challenge for her son to adapt a new environment with new peers in the near future.

#### Social relationship with other pupils and the barriers of social interactions of autism

*At the beginning of school attendance he was quite afraid of other children, but it was great that about 6 children he already know from the kindergarten, so it was easier to overcome it. He's got friends especially among girls, they like to help him. Since our son is on the first grade, there aren't any severe problems, he's getting better in social situations, all the children are willing to help him and they usually doesn't solve his from time to time inappropriate behaviour. But I think, things are easier on the first grade because, the children still have just the one teacher and she's almost all the day with them, so she can solve any problems immediately.'*  
(Eliska, Parent 3)

Peers may consider their autistic pupils are emotional or childish because of their lack of social flexibility (e.g. repetitive behaviours or screams in inappropriate conditions) yet pupils with autism may not fully understand 'what is wrong' and 'why'. Chamberlain *et al.*, (2006) observe a game in the class in their research. They found that typical peers would firstly expect the autistic child to behave as 'normal' as everyone does and then 'draw a line between accommodation his differences and setting limits (p.239)' even the autistic boy was confused about the rules of the game and confused about how to reply to his peers. Still, pupils and the autistic boy have social interactions and also obtain some social norms. However, this observation shows typical developing peers would have a different standard to tolerate and treat children with SEN however on the other hand, it also implies SEN children in a way are ignored (e.g. without meaningful responses or conversations) in class to avoid conflicts yet



the problems still remain and this would cause some disagreement and discontent between SEN pupils and non-SEN pupils if the hard feelings increases and piles up. Children with autism receive lower peer acceptance however children with autism still have friendship, and they are not completely isolated. In addition, the friendship between typical pupils and autistic children should not be considered as the same as traditional friendship amongst non-SEN pupils. Hence, in an inclusive setting, teachers could create more opportunities for autistic peers and other typical pupils to interact and to gain an understanding for each other.

Research also shows that autistic children are interested in building up relationships but their social interactions with friends are not successful due to the lack of enough social competences, social skills, and social-emotional understanding thus having incapability to express their thoughts in order to make friendships (Bauminger, 2002; cited in Chiang, 2011). Parent 3 indicates *'the first problems appeared in the kindergarten, our son had problems with other children, he wasn't able to play with them, he didn't know how to contact them, sometimes he was rude and other children were afraid of him.'* Now parent 1's son is studying in a special school with seven peers with different diagnosis in his class. The general interactions between peers are quite well. They have international festival event including some tasks every year for people with disabilities therefore they travel to different places to attend the festival. As a teenager, he has also experienced the confusion dealing with girls as he does not know how to respond and react to this issue. *'This girl really likes him but he doesn't know what to do. He said he only likes mum and dad'* (Parent 1).

It is not easy to maintain a friendship, according to Chamberlain *et al.*, (2006), it involves high-level of social skills including provide with companionship, reliability, exchange feelings and thoughts, and interact with each other. Daniel & Billingsley (2010) also indicate relationship should be engaged with each other including involving in mutual interests and some social interactions such as chatting or laughing with in order to maintain friendship. Temple Grandin also mentions in a TED speech (Dxmonline, 2010) concerning how she learns social skills, *'I got social interactions through shared interests, so I rode horses with other kids and I made rocket models with other kids....'* Parent 2 describes *'I think he's quite lucky. All the classmates cooperate with him and he's one of them. But Vladimir is his REAL friend, the one he shares deeper friendship with.'* However, Parent 2 also indicates a social problem Lukas deals with. Generally speaking, in a social condition we share things (e.g. food, beverages, thoughts, or feelings) with people and in return which create a

reciprocal social interactions in order to improve and increase social contact with friends in order to maintain friendships. Parent 2's son finds it difficult to share snacks with his friend Vladimir even he is taught to do so as an appropriate social skill and behaviour. Instead of sharing snacks with Vladimir, he would rather throw snacks in the rubbish bin to temporarily solve the problem.

The social barriers of autism could cause the difficulties of building up and maintaining friendships with their typical developing peers, and cause lower peers acceptance in inclusive educational settings; however, public awareness of the features in relation to autism could bring an understanding if there is such a circumstance thus enabling typical developing peers understand and respect their peers with special educational needs.

# Chapter Five

## Evaluation & Conclusion

### 5.1 Introduction to the findings

This study is based on qualitative methodology as a framework to investigate the importance of parental involvement for the children concerning the social skills, daily living skills and academic improvement. Although the number of this study is relatively small, there is direct evidence of the positive influence of parental involvement. I classified the data into three themes discussing about the influence of meaningful parental involvement on children with autism spectrum disorder with respect to social skills, daily living skills, and academic aspect; the difficulties parents face, and the barriers of social interactions to autistic children. Results indicate that the influence of meaningful parental involvement is positive on children with autism spectrum disorder in relation to academic achievement, social skills, and daily living skills. This research also presents the difficulties parents face, their experience and the barriers of social interactions to autistic children.

### 5.2 Main research findings

Through literature reviews and data, three main themes emerged from parent participants' descriptions, as illustrated below.

#### Theme One: the influence of meaningful parental involvement on children with autism spectrum disorder

Theme one illustrates the positive influence of parental involvement on academic achievement, social skills, and daily living skills. Additionally, the strong connection and affection between families is also an influence for pupils with autism to build up a relationship starting from family and gradually to school and local community. There is a positive finding with regard to parental involvement. Parent respondents not only physically participate in the activities in school and at home such as school trips, reading, and homework

assistance, but also involve in children's daily life training to shape daily routines and daily living skills for autistic children. Additionally, parents attend some courses regarding autism every year such as educational programmes, parents counselling, and early intervention programme to gain more understanding of autism, to assist, to train, and to work with them. Parents have their strategies for autistic children to learn both academic knowledge and daily living skills step by step.

The findings are positive for daily living skills, academic perspective, and social skills which also support the reviews of literature. From literature review, parental participation as seen as an important factor connected with academic achievements such as reading and GPA. However, parents concerns and anxieties are more related to daily living skills such as to go to school by themselves, to do basic shopping, and to be with peers which also indicates parents mainly concern their autistic children's well-being, if they could be able to manage their lives independently; and afterwards concern about academic achievement. Literature reviews of the influence of parental participation on autistic children are positive. However, there is a gap between the strength and lack of parental involvement since the literature shows more positive influence of parental participation however seldom research mentions the influence of the lack of parental participation. Hence, it is recommended for future research studying on the lack of parental participation to have a balance.

### Theme Two: The difficulties parent face

Theme two emphasises on parent's difficulties including parents' experience having autistic children and parents' expectation and concerns for their autistic children. At first, parent respondents experienced shock and mainly needed to deal with their feelings. However, once parents determine to fully support their autistic children, they show strong positive attitudes and readiness towards dealing with the difficulties they were about to face. Particularly, after three parent respondents received official diagnosis of autism for their children, they were more certain to deal with the practical issues such as searching for the assistance and support from governments and local autistic organisations. However, parents point out there is still difficult to diagnoses autism since autism spectrum disorder covers a wide scope, ranging from non-verbal autism to average or of above average intelligence autism. Hence, parents have experienced a difficult time during doing assessment and

diagnostic process from doctors to doctors to find an answer, to receive an official diagnosis and to accommodate their children with autism due to difficulties of recognitions of autism thus resulting in having difficulties to receive support such as manual of disability and early intervention programmes.

Parents also constantly adjust themselves regarding their expectations to have a balance between their expectations and practical conditions. One of parent respondents changed her expectations to more specific, practical goals for her child to achieve. Parents also concern the social interactions between autistic children and their siblings, and the relationship between autistic children and their typical developing peers. Participants would teach or show their autistic children some social norms and behaviours by using some strategies to make the friendship and connect the relationship more closely, particular, sibling-autistic children relation.

### Theme Three: The barriers of social interactions of children with autism spectrum disorder

Theme three than considers the barriers of social interactions of children with autism spectrum disorder; investigate the effectiveness of the inclusive classroom setting, peer acceptance, social relationship with other typical developing peers; and the barriers of social interactions for autism.

Inclusive education provides typical developing pupils an understanding of how to cooperate, befriend with pupils with autism spectrum disorder, and learn to accept individual differences. Parent respondents express their agreements and the positiveness for inclusive environment for autistic children. Parents indicate their autistic children acquire the concepts and understand the 'normal' routines (e.g. social interactions with classmates) subconsciously through inclusive environment. It would be beneficial for autistic children to be included in an environment that similar to the environment they will be working in the society in the future.

It has been an issue with regard to appropriate placement for children with special educational needs. The challenges of inclusive education nowadays include policy-making, placement, curriculum, teacher's competence regarding special education, parent and pupil's acceptance, and the integration of resources. Inclusive setting could provide with more options for pupils with special educational needs.

Peer acceptance is another challenge for inclusive setting. A mother in Chiang's (2003) research describes every classmates is nice to his son but never include him in their games or invite him to a birthday party. It implies inclusive education could offer a physically accommodation for pupils with autism spectrum disorder in inclusive educational settings; however there is still a difficulty for typical developing pupils to accept SEN pupils wholeheartedly. Inclusive environment is significant for autistic children to increase the chances for social initiations, interactions and social skills if suitable models for autistic children are provided. However, literature reviews also illustrate that autistic children may feel great loneliness due to complicated social norms confusion and rejection from their peers.

These are three factors could cause the ignoring, isolation, rejection, or bullying from the typical developing peers. First of all, social inflexibility (e.g. repetitive behaviours or screams in inappropriate situations) of autistic pupils that causes low confidence, low self-esteem; and generally low physical competence of autism (i.e. motor and sensory impairment) causes less social attractiveness which may leads to ineffectiveness of making friendships and social interactions with others. Therefore, a skilled educator could create a meaningful inclusive setting providing and preparing social skills acquisitions for both children with SEN and non-SEN children to ensure the notion of inclusion. In addition, typical developing pupils should also be informed with regard to some features and conditions of autism spectrum disorder to understand individual differences. Secondly, some features of autism such as 'either black or white' concept which leaves no room for further discussion and interactions with typical developing peers. Moreover, autistic pupils certainly have interests in establishing friendship or partnership; however they do not engage too much playing with the peers. In lower Years in primary stage, younger pupils generally show more affection to help and support each other. Through reviewing of literature, there is a positive finding in relation to the social relationship in class in Year 1. However research also shows when children turn to adolescent, children start to notice the differences (i.e. maturity, secondary sexual characteristics, and appearances) and select friends they would like to be engaged with. Autistic pupils would be considered as childish by their typical developing pupils as parent 2's son experienced. Thirdly, complicity of social initiations and interactions causes confusion for autistic pupils to standardise the social behaviours. It is not easy to maintain traditional friendships, which includes high-level of social skills, companionship, reliability and exchange feelings and thoughts. Typical peers at first would accommodate autistic children's differences yet there is no standard and consistency every time and every condition

since there is no fixed social behaviours in different circumstances anyway. Moreover, autistic children have a difficulty to judge what to perform in different situations containing social interactions due to the lack of enough social competences. Therefore it may cause great confusions for pupils with autism regarding what rules to follow. Typical peers may consider pupils with autism as weirdoes or geeks especially if the autistic children are with average or of above average intelligence.

### **5.3 Conclusion**

In conclusion, parental involvement has its significant influence on SEN children and the benefits of parental participation are still more than the disadvantages. Results of this investigation can be interpreted to suggest further research on the perspective of lack of parental participation to have a balance because the literature illustrates more positive influence of parental participation yet lack of parental participation is not addressed much. This research investigates the influence of meaningful parental involvement on children with autism, and illustrates the difficulties parent have experienced, and the barriers of social interactions of children with autism spectrum disorder in inclusive educational settings. As Parent 3 indicates, *I think it's very important ó that at pedagogics universities not only students of special education hear about autism, but all the students. Because it's very likely that in their future practise they will meet a student/pupil with AS and they should be prepared.* Rovinelli & Gitterman (2011) suggest parents who have children with special needs firstly thinking about the interventions they need, and combining public and private support/ resources to access to the services provided. 'At the same time, society would begin to understand the need to embrace all individuals, including those with autism (p. 267).'

# Bibliography

- Allred, P., & Edwards, R. (2000). A Typology of parental involvement in education centring on children and young people: Negotiating familialisation, institutionalisation and individualisation. *British Journal of Sociology of Education*, 21 (3), 435-455.
- Alderson, P & Goodey, C. (1999) Autism in Special and Inclusive Schools: 'There has to be a point to their being there', *Disability & Society*, 14:2, 249-261
- American Psychiatric Association. (2000) *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition Text Revision. Washington, DC, APA.
- Baker, A. (1997) Improving Parent Involvement Programs and Practice: A Quantitative Study of Parent Perceptions, *School Community Journal*, Volume 7(1).
- Barnard, W. (2004) Parent involvement in elementary school and educational attainment. *Children and Youth Services Review*. 26(2004). 39-42.
- Barnes, C., & Mercer, G. (1996) Introduction: Exploring the divide. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability* (pp. 1-16). Leeds: The Disability Press.
- Baron-Cohen, S., & Bolton. P. (1993) *Autism: the facts*. Oxford: Oxford University Press.
- Baron-Cohen, S. Leslie, A. and Frith, U. (1985) Does the autistic child have a 'theory of mind'? *Cognition* 21,37-46.
- Bandura, A. (1977) *Social Learning Theory*. Englewood Cliffs, NJ: Prentice Hall.
- Bauman, M., & Kemper. T., *et al.* (1994, 2005) *The Neurobiology of Autism*. Second Edition. Baltimore and London: The John Hopkins University Press.
- Bennett, A. (2012) Parental Involvement in Early Intervention Programs for Children with Autism. *Master of Social Work Clinical Research Papers*. Paper 113.
- Blatt, G., *et al.* (2010) *The Neurochemical Basis of Autism: From Molecules to Minicolumns*. New York: Springer



- Bogdan, R., and Biklen, S. (1992) *Qualitative research for education: An introduction to theory and methods*. Boston: Allyn & Bacon.
- Bronfenbrenner, U. (1979) *The ecology of human development: experiments by nature and design*. Cambridge, Mass: Harvard University Press.
- Bryman, A. (2012) *Social research methods*. 4<sup>th</sup> edition. Oxford: Oxford University Press.
- Buggey, T., G. Hoopes, M. Sherberger, & S. Williams. (2011) Facilitating Social Initiations of Preschoolers With Autism Spectrum Disorders Using Video Self-Modeling. *Focus on Autism and Other Developmental Disabilities*, 26(1) 25-36.
- Bury, M. (2000) On chronic illness and disability, in: C. E. Bird, P. Conrad & A. M. Fremont (Eds) *Handbook of medical sociology* (5th edn) (New Jersey, PA, Prentice Hall).
- Bushwick, N. (2001) Social learning and the etiology of autism. *New Ideas in Psychology*. 19. 49-75.
- Campbell, J., J. Ferguson, C. Herzinger, J. Jackson, & C. Marino. (2005) Peers' Attitudes Toward Autism Differ Across Sociometric Groups: An Exploratory Investigation. *Journal of Developmental and Physical Disabilities*, 17(3) 281-298.
- Chamberlain, B., C. Kasari, & E. Rotheram-Fuller, (2006) Involvement or Isolation? The Social Networks of Children with Autism in Regular Classrooms. *Journal of Autism Developmental Disorder*. 37(3) 230-242.
- Chen, H. (2003) 身心障礙學生家長與教師之合作. [The cooperation between teachers and parents who have children with SEN] 17(2), 26-31.
- Chen, Y. (2006) 自閉症幼兒母親對親子互動信念之研究. [A study on mothers' faith of parent-child with autism interaction ].*花蓮教育大學學報*. 23 期,167-190.
- Chiang, C. (2008) The Autism Research in Taiwan: Literature Overview. *Research in Applied Psychology*. 40(4) 165-196.
- Chiang, I. (2003) Effects of a therapeutic recreation intervention within a technologybased physical activity context on the social interaction of male youth with autism spectrum disorders. Unpublished doctoral dissertation. Indiana University, Bloomington, IN.
- Chiang, I. (2011) 「不想成為班上的小白兔!」:以符號論釋自閉症學童在融合教育中友誼建立之挑戰。 [‘Don’t Want to be a Pet Rabbit in Class!’: Using Symbolic

- Interpretation to Explore the Challenges of Friendship Building on Students with Autism in Inclusive Education]. *Bulletin of Special Education*. 36(3), 87-114.
- Cihak, D., C. Smith, A. Cornett, & M. Coleman. (2012) The Use of Video Modelling With the Picture Exchange Communication System to Increase Independent Communicative Initiations in Preschoolers With Autism and Developmental Delays. *Focus on Autism and Other Developmental Disabilities*, 27(1) 3-11.
- Clough, P. & Nutbrown, C. (2004) 'Special educational needs and inclusion: multiple perspectives of preschool educators in the UK', *Journal of Early Childhood Research*, 2(2), 191-211
- Comer, J.P. & Haynes, N.M. (1991) Parent Involvement in Schools: An Ecological Approach. *The Elementary School Journal*, 91(3), 271-277
- Cohen, L, Manion, L, & Morrison, K. (2007). *Research Methods in Education*, London : Routledge.
- Comer, J & Haynes, N. (1991) Parent Involvement in Schools: An Ecological Approach. *The Elementary School Journal* , 91(3), 271-277
- Creswell, J. (2009). *Research design: qualitative, quantitative, and mixed methods approaches*, London: Sage.
- Daniel, L. & Billingsley, B. (2010) What Boys With an Autism Spectrum Disorder Say About Establishing and Maintaining Friendships. *Focus on Autism and Other Developmental Disabilities*. 25(4) 220-229.
- DfES (2001) *Special Education Needs: Code of Practice*. Nottingham: DfEs.
- Dubin, N. (2007) *Asperger syndrome and bullying: Strategies and solutions*. London, Philadelphia: Jessica Kingsley Publishers.
- Dxmonline, (2010) *世界需要不同的思考*[world needs different thinkings]-Temple Grandin. [YouTube] Available at: <http://www.youtube.com/watch?v=5FDivECOpqA>, (accessed: 21/09/13)
- Epstein, J. L., & Dauber, S. L. (1991) School programs and teacher practices of parent involvement in innercity elementary and middle schools. *The Elementary School Journal*, 91(3), 289-305.

- Europe Agency for Development in Special Needs Education. (2010) *Identification of special educational needs - Czech Republic*, Available at: <http://www.european-agency.org/country-information/czech-republic/national-overview/identification-of-special-educational-needs> (accessed: 15/07/13)
- Fan, X, and Chen, M. (2001) Parental Involvement and Students' Academic Achievement: A Meta-Analysis, *Educational Psychology Review*, Volume.13(1).
- Finkelstein, V. (2001a) *A personal journey into disability politics*. The Disability Studies Archive UK, Centre for Disability Studies, University of Leeds. Available online at: [www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm](http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm) (accessed August 2003).
- Fitzgerald, D. (2004) *Parent partnership in the early years*. London; New York: Continuum.
- French, S. (1993) Disability, impairment or something in between? In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers: Enabling environments* (pp. 17-25). London: SAGE Publications.
- Frith, U., & Hill. E. (2003) *Autism: mind and brain*. New York: Oxford
- Hradec Králové University, (2008) *Country Report: The Czech Republic*, The Czech Republic: Educational Policies that Address Social Inequality (EPASI)
- Hornby, G. (2000) *Improving parental involvement*. New York, NY: Cassell.
- Hou, S. (2007) 家長參與學校教育的意義與途徑 [The methods and meanings for parents to participate in school education]. 24(2), 15-11.
- Hsu, M., & Hsia, C. (2000) *Teaching Models of Inclusive Education: The Case of Autistic Children Integrated into Regular Class*. Kao-hsiung: Fu-Wen.
- Jacob, M. (2010) *Parental Expectations and Aspirations for their Children's Educational Attainment: An Examination of the College-Going Mindset among Parents*, PHD Thesis, University of Minnesota
- Jacob, S., & S. Furgerson. (2012) *Writing Interview Protocols and Conducting Interviews: Tips for Students New to the Field of Qualitative Research*. The Qualitative Report 2012 Volume 17, T& L Art. 6, 1-10.

- Johnson, J., E. Blood, A. Freeman, & K. Simmons, (2013) Evaluating the Effectiveness of Teacher-Implemented Video Prompting on an iPod Touch to Teach Food-Preparation Skills to High School Student With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 28(3) 147-158.
- Kamps, D., P. Barbetta, B. Leonard, & J. Delquadri. (1994) Classwide Peer Tutoring: An Integration Strategy to Improve Reading Skills and Promote Peer Interactions among Students with Autism and General Education Peers. *Journal of Applied Behaviour Analysis*. 27(1) 49-61.
- Kamps, D., B. Leonard, S. Vernon, E. Dugan, J. Delquadri, B. Gershon, L. Wade, & L. Folk. (1992) Teaching Social Skills to Students with Autism to Increase Peer Interactions in an Integrated First-grade Classroom. *Journal of Applied Behavior Analysis*. 25(2) 281-288.
- Kent, Tim. (26 November 2012) *Introduction to the Educational Action Research/Practitioner Research Approach*. [PowerPoint slides]. Presented at a RME2 workshops lecture at University of Roehampton
- Keyser, J. (2001) 'Creating partnerships with families: problem-solving through communication', *Childcare Information Exchange*, No. 138. pp.44-7
- Krantz, P., M. MacDuff, & L. McClannahan. (1993) Programming participation in family activities for children with autism: parents' use of photographic activity schedules. *Journal of Applied Behaviour Analysis*, 26, 137-138.
- Kvale, S. (1996) *InterViews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks: SAGE.
- Lin, H., M. Knox, J. Barr, M. Chiu, & K. Chung, (2006) '*Living with -The Wall- The Experiences and Perspectives on Social Relationships of Two Taiwanese People with a Physical Disability*', Presented at: Proceedings Social Change in the 21<sup>st</sup> Century Conference 2006, Queensland University of Technology.
- Marshall, F. (2004) *Living with autism*. London: Sheldon.
- Maykut, P, and Morehouse, R. (1994) *Beginning Qualitative Research: A Philosophic and Practical Guide*, London: Falmer Press

- McCoy, E., & Cole, J. (2011) *A Snapshot of Local Support for Literacy: 2010 survey*. London: National Literacy Trust.
- McLeod, S. (2007) *Vygotsky*. Retrieved from <http://www.simplypsychology.org/vygotsky.html>
- McConnell, S. (2002) Interventions to Facilitate Social Interaction for Young Children with Autism: Review of Available Research and Recommendations for Educational Intervention and Future Research. *Journal of Autism and Developmental Disorders*, 32(5), 351-363.
- Mesibov, G., L. Adams, & E. Schopler (2000) Autism: A Brief History, *Psychoanalytic Inquiry: A Topical Journal for Mental Health Professionals*, 20(5), 637-647.
- Ministry of Justice, Laws & Regulations Database of The Republic of China: *The Special Education Act*, Available at: <http://law.moj.gov.tw/LawClass/LawContent.aspx?pcode=H0080027> (accessed: 17/11/2012)
- Munn, P. (1993) *Parents and Schools: Customers, Managers or Partners?* London: Routledge.
- Ozonoff, S., & Jensen, J. (1999) Brief Report: Specific Executive Function Profiles in Three Neurodevelopmental Disorders. *Journal of Autism and Developmental Disorders*, 29(2), 171-177.
- Patton, M. (1987) *How to Use Qualitative Methods in Evaluation*, London: Sage.
- Punch, K. (2009) *Introduction to Research Methods in Education*, Los Angeles: Sage.
- Reynolds, A. (1992) Comparing Measures of Parental Involvement and Their Effects on Academic Achievement. *Early Childhood Research Quarterly*, 7, 441-462.
- Ritvo, E. (2006) *Understanding the nature of autism and Asperger's disorder: Forty years of clinical practice and pioneering research*, London; Philadelphia: Jessica Kingsley.
- Roberts, K. (2010) Topic Areas to Consider When Planning Transition From High School to Postsecondary Education for Students With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*. 25(3), 158-162.

- Robins, B., K. Dautenhahn, R. Boekhorst, & A. Billard. (2005) Robotic assistants in therapy and education of children with autism: can a small humanoid robot help encourage social interaction skills? *Univ Access Inf Soc* (2005) 4:105-120.
- Robson, C. (1993) *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*, Oxford: Blackwell.
- Robson, S, and Foster, A. (1989) *Qualitative Research in Action*, London: Edward Arnold.
- Rogers, C. (2007) *Parenting and Inclusive Education: discovering difference, experiencing difficulty*. Basingstoke: Palgrave Macmillan
- Rovinelli, N., & Gitterman. A., (2011) *Mental Health and Social Problems: A Social Work Perspective*. Oxford: Routledge
- Sansosti, F., K. Lavik, & J. Sansosti. (2012) Family Experiences Through the Autism Diagnostic Process. *Focus on Autism and Other Developmental Disabilities*. 27(2) 81-92.
- School Standards and Framework Act (1998) *Home-School Agreements*
- Sénéchal, M. & LeFevre, J. (2002) Parental Involvement in the Development of Children's Reading Skill: A Five-Year Longitudinal Study. *Child Development*, 73(2), 445-460
- Sperber, D., & Wilson, D. (1995) *Relevance: Communication and Cognition*. Oxford: Blackwell.
- Su, X. & Zhou, S. (1994) 教學策略與學前自閉症個案之學校適應 [A case study: teaching strategies and the adjustment for an autistic pupil in school.] *輔仁學誌*, 27 期, 107-142.
- Sun, S. (2009) 專家學者對普通班教師之身心障礙學生家長參與知能培育的一致性研究 [A study on parents, whose SEN children are in general class, participate in SEN counselling and seminar.] *12(3)*, 187-212.
- Trembath, D., C. Germano, G. Johanson, & C. Dissanayake. (2012) The Experience of Anxiety in Young Adults With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*. 27(4) 213-224.

- Thomas, G. (2009) *How to do your Research Project: A guide for students in education and applied social sciences*. London; Los Angeles: SAGE.
- The *Salamanca Statement* and its accompanying Framework for Action on Special Needs Education (UNESCO, 1994)
- Vincent, C. (1996) *Parents and Teachers: Power and Participation*. Basingstoke: Falmer.
- Vygotsky, L. (1962) *Thought and Language*. Cambridge MA: MIT Press.
- Vygotsky, L. (1978) *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.
- Weiss, R (1994) *Learning from Strangers: The Art and Method of Qualitative Interview Studies*. New York: The Free Press.
- Williams, D.L. & Chavkin, N.F. (1989) Essential elements of strong parent involvement programs. *Educational Leadership*, 47, 18-20
- Wolfendale, S. (1983) *Parental Participation in Children's Development and Education*. New York; London: Gordon and Breach Science Publishers.
- Wu, S., & Yang, T. (2002) 鷹架式遊戲團體對高功能自閉症兒童象徵遊戲影響之個案研究 [The Influence of a Scaffolding Play Group on the Symbolic Play of a High-Functioning Autistic: A Case Study], *特殊教育研究學刊*, Vol 22, p. 75-101.
- Wu, W. (2007) Inclusive Education in Taiwan. *Chinese Education and Society*, 40(4). P.76-96.
- Yuan, C. (2002) *Big hand in small hand: I and my son, Sao-Yi*. Taipei, Taiwan: Teacher Chang Culture.

# Appendix A

## Participant Consent Form

The Parents  
-----

Prague

23<sup>th</sup> September, 2013.

Dear Madam/Sir,

### **Re: Research Project Interview**

I am a student at Charles University, and I am conducting interviews for my Erasmus Mundus Masters in Special and Inclusive Education research project. Below are details of the research project.

### **Research title:**

The Influence of Parental Participation on Pupils with Autistic Spectrum Disorder.

### **Background of the study**

The interest in this topic has been motivated by my personal experience working with autism. Also I wish to gain the findings and perspectives of the parental influence on autism.

### **Purpose of the study**

The purpose of the study is to find out how parental participation influence autistic children. Therefore, related questions will be asked about your experiences with regard to autism. The interview is designed to be approximately one hour.

### **Confidentiality Issues**

All the information will be kept confidential and the data in a secure place. Upon completion of this project, all data will be destroyed. Names of interviewees will be withheld and sensitivity will also be used when describing the background context so interview participants will not be easily identified.

### **Participant Rights**

Participant is voluntarily however, please feel free to expand on the topic or talk about related ideas. Also, if there are any questions you would rather not answer or that you do not feel comfortable answering, please say so and we will stop the interview or move on to the next question, whichever you prefer.



**Participant's Agreement:** (Please tick the box to indicate your consent)

- I am aware that my participation in this interview is voluntary. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.
- I understand the intent and purpose of this research.
- I am aware that the data gathered in this study are confidential with respect to my personal identity unless I specify otherwise.
- If I have any questions about this study, I am free to contact the student researcher (Yunya Huang: nicole7246@gmail.com, mobile: +4475 74 911 932)
- I have been offered a copy of this consent form that I may keep for my own reference.
- I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today's interview.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Interviewer's signature

\_\_\_\_\_  
Date

# Appendix B

## Interview Guide

<p><b>Introduction Key Components</b></p> <ol style="list-style-type: none"> <li>1. Thank you</li> <li>2. Your name</li> <li>3. Purpose</li> <li>4. Confidentiality</li> <li>5. Duration</li> <li>6. How interview will be conducted</li> <li>7. Opportunity for questions</li> <li>8. Signature of consent</li> </ol>	<p>I want to thank you for taking the time to meet with me today. My name is Yunya and I would like to talk to you about your experiences regarding autism, which is the research I'm currently doing. Specifically, I'm interested in the influence of parental participation on autism. I hope the research will be beneficial and it can be used for related teaching/study in the future.</p> <p>The interview should take less than an hour. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possible write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments.</p> <p>All responses will be kept confidential. This means that your interview responses will only be shared with me and I will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time.</p> <p>Are there any questions about what I have just explained? Are you willing to participate in this interview?</p>
--	--